RELATIONSHIPS, CAREGIVING AND MULTIPLE SCLEROSIS:

GENDER AND PERCEPTIONS OF CARE

by

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ABSTRACT

This qualitative research study attempted to understand and unpack the caregiving experience in the illness of Multiple Sclerosis (MS). Ten couples were interviewed separately and later as a dyad to discuss care, care responsibilities and support systems to see how gender influenced either the caregiving or care receiving experience. The purpose of this research was to explore, develop, and understand perceptions of care between care providers and caregivers of MS under the lens of feminist care theory/ethics of care within a social model of disability.

Caregivers and those diagnosed with MS experience the caregiving relationship in a variety of ways where gender does indeed influence the experience of care. Gender provides a dimension for understanding the social construction of the disease including daily responsibilities of both the care giver and care receiver. Participants were acutely aware of gender when required to complete a care event or task outside of traditional gender roles. The social construction of gender provided a point of awareness for participants to examine care roles. Those tasks falling outside traditional gender roles were frequently brought to consciousness and provided an area of potential provocation.

Additionally, this research examined care needs and the role of social support in the care experience. Care needs differed among participants depending on the availability of resources. Resources include: financial, time and social support. Access to these various resources affected the outcome of the care situation. Gender in turn influenced the understanding and use of resources as a dynamic in the experience. The social construction of gender also affected participants' ability to clarify and understand their experience in terms of accessing resources.

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CHAPTER 1

INTRODUCTION

In the United States, 200 people are diagnosed with Multiple Sclerosis (MS) each week (NMSS 2009a). Women, typically society's caregivers, are afflicted with MS at twice the rate of men, which places many women in the reverse position of requiring care. In this research, I examined the experience of caring between caregivers and care receivers, and explored whether that experience was influenced by gender differences within the specific context of multiple sclerosis patients. Furthermore, I examined the care and social support needs of caregivers and care receivers.

MS is a widely expansive disease relying on the care assistance of non-professionals. The National Multiple Sclerosis Society (NMSS) estimates that 2.5 million individuals have Multiple Sclerosis worldwide. Approximately 400,000 of those reside in the United States. Between 5-10% of those with MS are unable to remain at home and require nursing home care (NMSS 2009c). Therefore, 90-95% of individuals with MS remain in their own homes requiring some type of care assistance. Most often the responsibility of providing home care falls on the family and loved ones. The experiences of this group of unpaid-nonprofessional caregivers will be explored and examined in this qualitative research study.

Unpaid-nonprofessional caregivers of MS patients are responsible for a wide variety of care activities including medical care, emotional support, physical assistance and financial needs. The care provider can be burdened with the many needs of the MS patient. Developing understanding and providing support to the caregiver relationship will benefit both patient and caregiver alike. Critical to this understanding is the underlying question of whether gender differences exist in the care experience. Extensive research on care and caregivers has been conducted in the past focusing on the general care phenomena (Cummins, 2001; Dobrof, Ebenstein, Dodd, & Epstein, 2006; Pearlin, Mullan, Semple, & Skaff, 1990; Stone, Cafferata, & Sangl, 1987). However, specific research on MS care providers is less readily available; research available on the MS care relationship encourages further exploration. Studies conducted by Long and Miller (1991), Chipchase and Lincoln (2001) and O'Hara et al. (2004) suggested the role and perceptions of family care providers for MS patients should be considered further. The dynamics of providing care for this population is unique because of factors including: age of onset, gender connection to the illness, and recent advances in medication management that delay the progression of the illness. MS is a disease unlike others and a basic understanding of this disease helps establish the foundation of this research.

Overview of Multiple Sclerosis

MS is the most common neurological disease in young adults. It is first diagnosed between the ages of 20 to 50 years. The disease is not contagious or directly inherited although there are several factors that may help determine who eventually contracts this disease. These factors include gender, genetics, age, geography, and ethnic background.

The prevalence of MS is higher for women than men (Nodder, Chappel, Bates, Freeman, Hatch & Keen, 2000), with a ratio of at least two women to every one man. Although MS is not directly inherited, genetics do play a role in determining who develops the disease. The overall risk for developing MS increases from 1/750 for the general population to 1/40 if a close relative (parent, child or sibling) has MS. MS is more common in individuals who live in northern latitudes and less common for those who reside closer to the equator. MS occurs in most ethnic groups although it is more common in Caucasians of European ancestry (NMSS 2009d).

MS is a progressive yet unpredictable neurological condition that results in a wide array of symptoms and disabilities. The disease course places a burden not only on those with MS but on their caregivers as well. Severity and symptoms of MS vary greatly from patient to patient and include fatigue; numbness; walking; balance and coordination problems; bladder problems; vision problems; dizziness; vertigo; sexual dysfunction; pain; impaired cognitive function; emotional changes; depression; and spasticity (NMSS 2010b). With recent advances in medication management, individuals with multiple sclerosis are having fewer and less severe exacerbations. Furthermore, medications delay the onset of significant disability and MS patients are maintained in their own home longer, requiring less institutional care. This is good news for the MS patient; however; it places additional responsibilities on the home care provider. Eighty percent of informal home care is provided by live-in relatives, primarily the MS patient’s partner (Carton, Loos, Pacolet, Versieck, & Vlietinck, 2000). The responsibility of in home care falls to the patient’s loved ones and it is that unpaid- nonprofessional care relationship upon which this research will focus.

The random nature of the disease makes it challenging for patients and loved ones. It is difficult to predict the individual course of MS. The disease process, symptoms and severity vary significantly from one individual to another. Although rare, some individuals with severe disability may experience infections and die prematurely. The National Multiple Sclerosis Society reports that the overall life expectancy is 95% of normal life expectancy (NMSS 2010b). The effects of MS are more insidious. MS generally impairs the individual’s ability to complete the activities of daily living.

Two Women with Multiple Sclerosis and Their Caregivers: Conflicting Normative Expectations (Abma, Oeseburg, Widdershoven, Goldsteen, & Verkerk, 2005) provides two case studies of women with MS to further understanding into the illness. Kathy is a 48-year-old woman with MS who was diagnosed 20 years ago. She is ambulatory but requires the use of a wheelchair or walker outside her home. She has hired professional caregiving assistance a few hours a week. Kathy used to work full time but has had to reduce her workload to two afternoons a week. In the last 2 years, Kathy has frequently used sick leave as her condition has worsened. She experiences spasticity in both hands and she is extremely tired. She wonders if she will be able to continue working. Kathy’s mother worked her entire adult life and Kathy perceives work as important by providing status and contributions to society. Kathy defines herself as an ambitious woman but she acknowledges that going to work requires so much energy that she is unable to maintain contact with friends and family members. MS diminished aspects of life that Kathy values, which results in her feeling powerless and grieving her losses.

Anne is a 39-year-old woman with the diagnosis of MS for over 17 years. She describes herself as someone who has learned to live with MS. Anne lost her job at the age of 28 when she was first diagnosed with the disease. Anne reports, "I am not solely an MS patient. I am also Anne who wants to do other things in life, in my spare time. I do not always want to be involved with MS that is just a part of me." She yearns for an identity outside of her disease. Anne goes on to say, "On a daily basis, I am confronted with the dependence on others, which is a fact of life, and that help I need from others" (Abma et al., 2005:486).

Another example of an MS experience is beautifully illustrated by the book and movie, *A Genius in the Family*. Helen Meekosha offers a review of both the book and movie in her article, "A Disabled Genius in the Family: Personal Musings on the Tale of Two Sisters". Meekosha summarizes the story of Jackie, a famous cellist. Jackie's sister, Hilary, believes that without Jackie's cello, Jackie would be nothing. Jackie's husband tells Jackie, "You wouldn't be you if you couldn't play." As Jackie's MS progresses, playing the cello becomes impossible and Jackie is unable to get her fingers around the strings. Jackie says, "I just want to play again. I'll play the fucking triangle. I just want to play music again"(Meekosha, 2000:814). All three of these narratives offer a brief glance into the lives of those living with MS. That experience is shaped by the family care the patients receive.

Overview of Multiple Sclerosis Caregiving

Providing care for a loved one with MS can be both deeply satisfying and emotionally and physically exhausting. Caregiving activities for a loved one with MS vary with the severity of the disease. Caring for someone with few functional difficulties may simply involve giving injections or offering support. Providing care for someone with a more severe level of impairment may involve assistance with daily living activities such as toileting, dressing, bathing, and transferring. Individuals with significant impairment from MS are able to remain at home for long periods of time providing they have the assistance of some type of care provider, either paid-professional or unpaid-nonprofessional. Typically, individuals with illness prefer the assistance of a loved one as the primary caregiver.

Considerable amounts of care, provided to people with MS, are informal in nature and most patients want to be cared for in a familiar environment. There are numerous benefits to both society and the MS patient in utilizing unpaid-nonprofessional care. Specifically, unpaid-nonprofessional care is care provided by loved ones, usually family members. This type of care is termed “informal” because care is arranged by loved ones and typically no financial reimbursement is received. Health care providers recognize the psychological and social advantages of utilizing informal care (Carton et al., 2000). Not only do individuals prefer informal care, but social support provided by family care relationships also becomes a major factor in overall adaptation to physical illness (Long & Miller, 1991). Furthermore, individuals with MS reported higher quality of life measurements when they perceived having more social support (Schwartz & Frohner, 2005). Informal care is crucial not only in maintaining patients with MS in the community but additionally providing a significant cost savings as opposed to paid or institutional care.

Providing care for a chronically ill individual is generally viewed as a stressful situation for caregivers and has a profound impact on not only the patient's social roles but his or her family's well-being (Hakim, Bakheit, Bryant, Roberts, McIntosh-Michaelis, Spackman, Martins, & McLellan, 2000). Caregivers of individuals with a disability are at risk of increased stress and depression as well as poorer quality of life measurements (Cummins, 2001). The effects of providing care are often overwhelming for the caregiver, resulting in changing roles, restrictions, economic concerns, employment problems and the decline in social relationships (O'Brien, 1993). Specifically, MS has a profound effect on caregivers of patients with MS, including psychological stress, lack of social support, social isolation, and profound loss issues. The well-being of the overwhelmed family caregiver is an ongoing major health issue (O'Brien, 1993). The question of how gender differences affect the overall experience of providing and receiving care remains unanswered.

Patients are typically diagnosed with MS as young or middle aged adults around the time individuals are establishing intimate relationships and partnerships. Time of diagnosis coincides with the potential for significant changes and life stressors, such as marriage, child rearing, providing financial support to family and career establishment. Patients and families are at a time in life when they are ill prepared to deal with this debilitating chronic condition, which makes caregiving within the MS population of particular interest to evaluate and research. Gender roles are especially significant at this time in life when individuals are raising children and tending to the demands of work, family and marriage.

The role that social support plays in the MS care relationship is another area of concentration for the research. According to Long and Miller (1991), social support is significant to the well-being of MS patients. Social support was found to be a major factor in adaptation to physical illness, and the lack of family support is useful in predicting a tendency toward suicidal behavior in MS patients. Although socially supportive relationships are frequently disrupted and deteriorate within the stressful nature of providing care, MS patients have higher quality of life measures when utilizing family support systems (Long & Miller, 1991). Despite the research indicating the need for social support among MS patients, there is a lack of literature exploring the needs of the MS patient caregivers. Given the positive relationship between social support and adaptation among individuals with MS, it is reasonable to assume that caregivers could also benefit from social support to prevent feeling stressed and isolated, and to assist the caregiver in managing his or her feelings related to grief and loss. Additionally, providing a support system for the caregiver ultimately benefits both the individual with MS and society, because patients prefer the assistance of a loved one, and the expense to society is reduced as a result of care being provided by a loved one without any upfront cost.

Available social support is not always utilized by family caregivers when needed. O’Hara, De Souza, and Ide (2004) concluded that although MS patients are receiving considerable amounts of care by family members, those caregivers are not receiving social support from professionals. Moreover, these caregivers report clinically significant levels of psychological stress related to the care of a partner with MS (Pakenham, 2001). Providing support to the caregivers is likely to reduce feelings of burden, stress and isolation of the caregiver. It allows the caregiver to continue in the care giving responsibility role, thus reducing the potential for the patient to require professional care assistance which is costly and could tax an overburdened disability insurance system.

Providing support to the care relationship is positively related to overall well-being of the care experience. Dobrof, Ebenstein, Dodd, and Epstein (2006) reported that supporting caregivers over time helped them cope with care of a loved one, and caregiver intervention for care of long-term or chronically ill patients enhanced caregivers' abilities to cope with caregiving responsibilities. Moreover, this research demonstrated a positive correlation between support services and caregivers' improved ability to cope, with 61% of participants reporting this improvement (Dobrof et al., 2006).

Community resources and available support varies from location to location. Nationally, varieties of online support networks are available for individuals with MS, loved ones and caregivers. The National Multiple Sclerosis Society has resources available for caregivers and recommends using the National Family Caregivers Association (NFCA), Caregiver.com, and the Well Spouse Foundation as caregiver resources for communities of support (NMSS 2010a).

Theoretical Framework

The current research will begin with a social model of disability perspective which argues that disability is a socially constructed problem, the construction of which has problematic consequences. As a result, society should seek to modify the conditions that lead to complications. From the social model of disability perspective, feminist theory will be used as the method of inquiry, specifically feminist care theory. Research on care and dependency has been connected to feminist theory in the 1980s, where providing care was seen as a “natural” feminine activity. Fine and Glendinning (2005) discuss the concepts of care receiver’s independence versus interdependence between the carer and patient and how this relationship dynamic emerged as a factor in providing care, i.e., is the care recipient dependent on care or is in fact the couple a care partnership that becomes interdependent on one another?

Feminist Carol Gilligan provided an understanding of care where the ideal care situation was seen as an activity of relationships, responding to need and sustaining connection. She identified a set of moral principles linked to care, distinctive but equal to the moral principles of both justice and rights. Gilligan believed that the “ethic of care,” which developed out of the appreciation and importance of care and caring labor, is most evident among women and is understood as part of the feminine process of moral development because it is based on the universal experience of having been cared for as opposed to the rule-based impersonal justice associated with masculine moral development. Gilligan did acknowledge the gender link is not exclusively feminine. She believed that development for both feminine and masculine moral identity could provide an integration of rights and responsibilities (Gilligan, 1982).

Other feminist scholars such as Virginia Held, Joan Tronto and Nel Noddings offer a response to Gilligan and challenge the origins of care as a “naturally” feminine activity. These scholars reject Gilligan’s dichotomy between female moral development based on care and male moral development based on justice. Additionally, they argue that care is a precondition for justice and the right to provide and receive care should be envisioned as a social justice issue (Fine & Glendinning, 2005; Held, 1995; Noddings, 2003; Tronto, 1993).

The theoretical framework for the “ethics of care model” provides the overarching theoretical lens to be used in this particular research. Looking at the role of caregiving and MS under a historically feminist lens is somewhat ironic in that a majority of patients with MS are women and caregivers are men who live in the same home as the person needing care, while nationally, most “nonfamily” caregivers are women who do not live with the person needing care. Buchanan, Radin, Chakravorty, and Tyry (2009) reported that the vast majority of informal caregivers for MS patients are spouses and over half of the spouses are husbands. The unique gender distribution among people who develop multiple sclerosis provides a rich environment in which to explore gender differences of care under the feminist ethics of care moral development model.

Significance of the Research

Clearly, social support provided by families and significant others is important to the overall well-being of an individual suffering from Multiple Sclerosis. However, the impact gender has on the care experience and on supporting the recipient of care is not understood. The role gender plays in care activities is underdeveloped and at times discredited.

Research is available on care for other illnesses; however, research on the specifics of multiple sclerosis care is rather limited. Little qualitative research is available on the subject of perceptions of care and support needs of unpaid family caregivers. Exploration of gender effects on the care phenomenon will provide insight and ultimately help develop greater understanding of the support and care needs for both the caregiver and receiver. The caregiver system is the link between the disabled person and society.

Understanding and strengthening that system is of particular interest and has potential ramifications for the disabled, their caregivers, practitioners, policymakers, researchers, and the greater community. Social workers will benefit from understanding the care experience and relationship of MS patients and their caregivers and be able to further utilize this information in providing assistance to MS patients and caregivers. Improving understanding will ultimately improve support opportunities.

Research Questions

This qualitative research study explores gender influences on the provision of care and perceptions of providing that care for patients with multiple sclerosis using a constructivist paradigm. It will investigate and discuss care experiences in MS care relationships and how gender influences this situation, which is especially beneficial for future social work practice. The study's research questions are as follows:

1.) How do caregivers and those diagnosed with MS experience the caregiving relationship?
2.) Does gender influence the provision of care and perceptions of care in providing for patients with multiple sclerosis?
3.) What are the care needs for both the MS caregiver and care receiver?
4.) What is the role of social support in the care relationship?

Organization of the Dissertation

The remainder of this thesis is organized into four chapters. Chapter 2 reviews the relevant caregiver research by looking at feminist care theory, care research, and specifically focusing on MS caregiving needs. Specific attention will be paid to gender differences. Chapter 3 describes the methods of this study, including the research questions and plans for analysis. Chapter 4 presents the findings from the 30 qualitative interviews with 10 couples, five female patients and five male patients. Additionally, predetermined and emerging themes will be discussed in Chapter 4. The fifth and final Chapter offers an analytical discussion of the study themes, discussing the strengths and limitations of the study and implications for the field of social work, and offers recommendations for future research.

CHAPTER 2

REVIEW OF THE LITERATURE

The following review of the relevant literature provides background and understanding to the process of providing care for individuals with MS and looks at the potential existence of gender differences in care from a feminist care theory perspective. I begin the literature review by presenting recent information on MS, which provides an understanding of the specifics of the disease and the needs of families and loved ones. Next, the literature review provides an explanation of the social model of disability from a feminist care perspective to further an understanding of disability and care needs. Care concepts are developed by exploring caregiving in a variety of illnesses and then specifically looking at care in individuals with MS. Additionally, literature that discusses gender differences in caregiving is explored, continuing with literature that specifically discusses gender differences in MS caregiving. Social support roles and benefits of unpaid-nonprofessional care to the community are also discussed. Finally, the review concludes by providing an understanding of caregiver needs and benefits of caregiver assistance.

Understanding Multiple Sclerosis

The National Multiple Sclerosis Society (NMSS) provides current comprehensive information about this illness (2010b). NMSS explains that multiple sclerosis is an autoimmune disease where the immune system attacks the brain or, more specifically, the myelin sheath which protects the nerve fibers in the central nervous system. The progression of the disease is variable and unpredictable. There are four courses of MS: relapsing-remitting, primary-progressive, secondary-progressive, and progressive-relapsing. Eighty-five percent of people experience relapsing-remitting MS, which is characterized by periods of relapse followed by periods of recovery. Ten percent of people with MS experience primary-progressive MS, which results in worsening neurological functions with no distinct times of relapse and recovery. Secondary-progressive MS generally occurs around 10 years after diagnosis of relapsing-remitting MS where the disease worsens steadily with or without remissions. Five percent of individuals experience progressive-relapsing MS, a rare, steadily worsening disease with clear attacks, and these individuals may or may not experience periods of recovery. MS (NMSS, 2010c). Advances in medication are hopeful and have proven to be effective at delaying the onset of severe symptoms of the disease.

Individuals are diagnosed with MS between the ages of 20-50 as symptoms initially present. It is not considered a fatal disease; however, individuals with MS face increasing limitations and reduced productivity as the disease progresses. Women are diagnosed with MS twice as often as are men. Genetic factors increase susceptibility to the disease, but there is no evidence that MS is directly inherited. Additionally, MS is not contagious. Geographic location may have some relationship to the disease as well, as people residing in northern latitudes have a higher incidence of being diagnosed than people residing closer to the equator. Researchers are investigating the relationship between vitamin D and sunlight in protecting against the occurrence of MS.

The causes of MS remain unknown although current research focuses on four factors: immunologic, environmental, infectious, and genetic. Immunologic studies determine which immune cells are mounting the attack on the myelin sheath. Environmental studies suggest that exposure to some environmental agent, such as vitamin D, before puberty may predispose a person to MS later in life. Infectious studies are evaluating the relationship between exposures to an infectious process as a potentially triggering factor in MS, and genetic studies are looking at the increase in prevalence of the disease if a close relative has MS. The prevalence varies geographically, reaching 5-30 incidents per 100,000 in North America and Northern Europe (Alguire & Epstein, 2006).

Disability and Theoretical Framework

Individuals with MS fall into a classification as disabled by society. Society attempts to understand how individuals with a disability fit into the general public. These understandings are formulated by developing and considering models of disability. Models of disability are not the same as theories of disability but are generators of hypotheses used to articulate an explanation of a phenomenon. Models of disability cannot be proven "true" but are representations of a mindset of thinking on disability. Two such models are widely accepted and understood in disability studies: the medical model of disability and the social model of disability (Fine & Glendinning, 2005;

Llewellyn & Hogan, 2000). The medical model views disability as a condition; it is the result of a physiological impairment due to an illness or injury. The social model of disability views disability as a socially constructed problem that is not the fault of the individual; rather; it is a condition that society can and should seek to modify. These models have a hold in disability research and stem from developmental psychology in systems theory (Llewellyn & Hogan, 2000). The social model of disability and systems theory become a starting point for this literature review.

The social model of disability challenges society to address how it can benefit the individual with a disability (Llewellyn & Hogan, 2000). Finkelstein (2001) presented a dual perspective on disability in which “you see disability fundamentally as a personal tragedy or you see it as a form of social oppression” (p. 4). Interpreting disability as a form of social oppression challenges society to take responsibility for change and provide necessary assistance for those who are disabled (Finkelstein, 2001; Thomas, 2004). The social model of disability presents a person-in-environment perspective of disability and encourages examination of the social systems supporting the individual with a disability.

The social system that seems most significant and first in the care of an individual with a disability is that of primary caregiver. The caregiver system becomes a link between the person with a disability and society. Strengthening that system is of particular interest and has potential ramifications for the disabled and for the larger system (Hakim et al., 2000). For the individual with a disability the question becomes, “Who is providing care and in what way is that care organized?” Interestingly, research on “care” and “caregiving” was linked to feminist theory in the early 1980s. The relationship of care was seen as a natural feminine activity although social model of disability activists are concerned this language is objectifying and oppressive (Fine & Glendinning, 2005). Additionally, Fine and Glendinning have proposed a link between feminist theory of care and a social construction of dependency. Although research on these two theoretical perspectives has generally maintained separate identities, Fine and Glendinning linked the two when they discussed the concept of interdependence among the disabled and the caregiver (2005).

Dependency is a concept used in the context of the caregiving relationship. The suggestion of providing care has more positive connotations than that of implying a dependent relationship, which suggests negative connection in terms of providing care. Further examining the dependence, independence and interdependence in the relationship of care demonstrates that dependency ties people together and is a normal, necessary social condition. Interdependence suggests the caregiving relationship provides a form of symbiotic benefits to both the care provider and the care receiver (Fine & Glendinning, 2005).

In examining gender differences of care, connections can be made between the concepts of dependence and interdependence with care for an individual with Multiple Sclerosis (MS). What is particularly interesting and somewhat ironic in this research is examining the co-constructed realities of caregiving and MS under a historically feminist lens where a majority of patients with MS are women: 78% of informal caregivers are spouses and half of these are male (NMSS 2009b). Therefore, more men are in the role of primary caregiver and one can explore if the concepts of feminist care apply to all caregivers, male or female, in this illness that affects more women than men.

Concepts of Care

Throughout time, providing care for individuals often became the responsibility of female family members: a wife, daughter or mother in most caregiving relationships. Researchers developed a connection between providing care and feminist theory in the 1970s and 1980s because care liability was seen as a natural feminine activity where the responsibilities and difficulties of women providing care were examined. Unpaid work provided by women for children, husbands, elderly and disabled family members was acknowledged by feminist theorists and coined as the "burden of care." Similarly, an alternative strand of feminist analysis provided the "ethics of care model" in reaction to emphasizing the burdensome features of providing care by focusing on the role and ethics of providing care (Fine & Glendinning, 2005). The ethics of care evolved around an appreciation of providing care and an insight that human experience is founded in a context of interdependence. Feminist pioneer Carol Gilligan provided insight into the concepts of self and one's morality by understanding that relationships provide purpose, understanding and benefit to the participants. Therefore, the ideal of care is connected to relationships when individuals identify needs and assist with those needs within the broad context of their relationship (Gilligan, 1982).

Other feminist scholars continued and critiqued Gilligan's discussion by challenging the feminine connection to care. If providing care is part of one's moral development, then why can't masculine moral development occur in the same manner? Masculine moral development is linked to justice, and scholars Noddings (2003), Tronto (1993) and Held (1995) view providing care as an issue of social justice. These scholars believe a relationship of providing or receiving care is characterized by vulnerability and disempowerment and care should be considered along with justice and rights. They further Gilligan’s discussion with the inclusion of the ethics of care as potentially part of masculine moral development (Fine & Glendinning, 2005; Held, 1995; Noddings, 2003; Tronto, 1993).

The ethics of care, a moral theory, recognizes that individuals require care for many years of their lives, not merely in childhood. Caring enables people to live and progress in life by attending and meeting needs of others for whom they take responsibility. The ethics of care cultivates characteristics of a caring person along with the skills necessary to provide care (Held, 2006). Providing care can be a natural activity that may progress to an obligatory event where goodness, right and wrong, morality and virtue, are all present. Additionally, within the ethics of care, providing care is transformed from a private activity done primarily by women to a wider context where relationships and responsibility are given social value. Furthermore, the ethics of care acknowledges that receiving and providing care is a precondition for social justice because caring relationships are subject to vulnerability and disempowerment (Noddings, 2003).

To provide an additional layer for consideration, social construction of gender or “doing gender” as discussed by West and Zimmerman provides an “understanding of gender as routine, methodical and recurring accomplishment” (p.125) where gender becomes embedded into the routine activities of daily responsibility. Certain care tasks are seen predominantly as male and female tasks while providing care activities are assumed by both men and women (West & Zimmerman, 1987). The demands of caregiving are not gender-specific and providing care can be a combination of physical and emotionally demanding work; however, society constructs the concepts of care as principally female events (Lorber & Moore, 2002).

Feminist care ethics provide an overarching perspective in thinking about care for purposes of this dissertation. The ethics of care theory focuses on development of institutions that are capable of sustaining caregiving relationships. Caregiving is the behavior that results from moral necessity and development discussed in the ethics of care framework. It is the behavior of providing care or specifically the care relationship that will be explored under the influence of gender in this research. That role of providing care is often overlooked by society although it is completely necessary for survival. Many individuals fill caretaking roles because they have become involved with dependent others and are viewed as acting out of the goodness of their own hearts. In the moral framework generally used by society, which involves individual versus reciprocal conceptions of justice and rights, providing care is undervalued and individual justice prevails. Because caregiving is necessary for well-being and quality of life, exploring the context and relationship of care is critical. Social construction of gender and illness additionally provided a framework to process the study’s interviews and allowed for deeper explanation of the gendered care experience.

Pearlin’s Caregiver Stress Process Model

The caregiving relationship has been subject to multiple research studies and concept development. Because people are living longer and families are committed to providing care for their loved ones, many researchers have explored the caregiving experience. Pearlin (1990) examined the caregiving relationship, specifically looking at stress among care providers in the caring relationship among family members. Pearlin viewed caregiving as a behavioral expression of commitment to the welfare of another when providing care refers to particular actions found in established roles of wife-husband or parent-child. At times, this role can expand to occupy a disproportionate amount of the relationship and result in unequally distributed burden and stress response. This stress experience varies among individuals with key characteristics of the caregiver influencing responsibilities and consequences. Age, gender, ethnicity, education, occupation, and economics influence the experience. Primary and secondary stressors as well as mediating conditions seemingly affect individuals in dissimilar ways. Pearlin explained that caregiver stress is not a unitary phenomenon; rather, it is a mix of experiences that vary among caregivers (Pearlin, Mullan, Semple, Skaff, 1990).

A conceptual view of Pearlin's Stress Process Model (see Figure 1) was adapted from Pearlin's article, "Caregiving and the Stress Process: An Overview of Concepts and Their Measures:" Pearlin's model, which initially began as an explanation for caregiver strain in family care associated with Alzheimer's disease, begins by understanding that the caregiver's experience is shaped by the **background and context** in which they experience the situation. An individual's experience with caregiving, family context and socioeconomic status all may contribute to the background and context. Background and context affect the way **primary stressors** are experienced by the caregiver. Primary stressors may include cognition, problematic behavior, daily living difficulties and other subjective experiences. **Secondary role strains,** which in turn are affected by primary stressors, involve the additional responsibilities required of the caregiver that are not

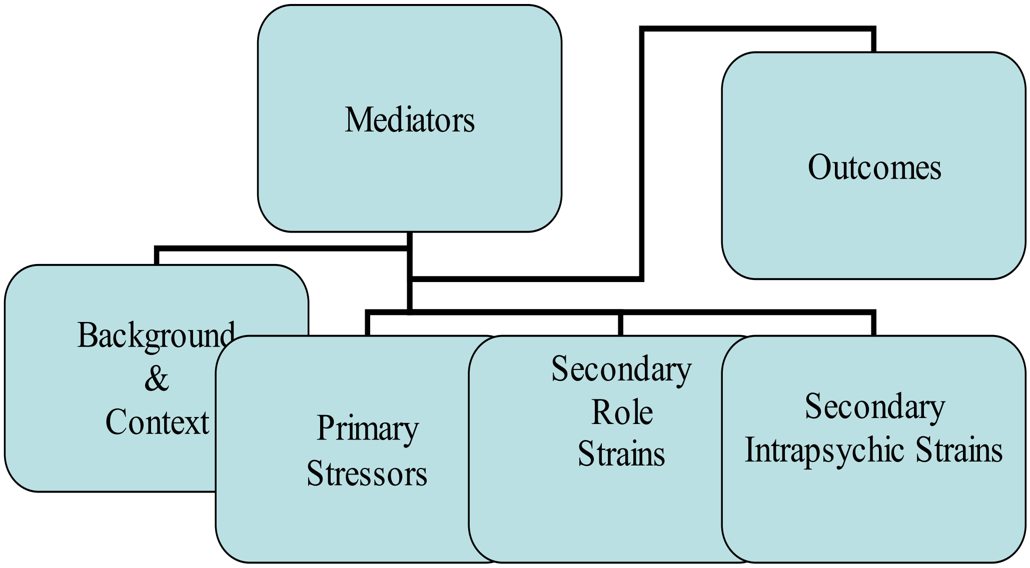

Figure 1: Pearlin's Caregiver Stress Process Model

Adapted from Pearlin's Stress Process Model (1990)

directly related to providing care. Economic problems, family conflict or job conflict may all be a part of secondary role strain. Self-esteem, mastery, competence and gain are examples of **secondary intrapsychic strains** which create an additional layer that contributes to the overall stress of the caregiver. These varying factors ultimately affect caregiver **outcomes**: anxiety, depression, cognitive difficulties, and physical health (Pearlin et al., 1990).

This model is useful in explaining the general process of caregiving that is common and shared across most caregivers regardless of individual illness. Pearlin's model accounts for individual differences in the background and context, which allows for flexibility in use with a wide range of care providing experiences in terms of how individual caregivers process and experience stress. Several studies have explored the use of Pearlin's Caregiver Stress Process in application with nursing home care, liver transplants and lesbian mental health respectively, which support the design as a tool for understanding and exploration (Bolden & Newsome Wicks, 2008; Gaugler, Anderson, Zarit, & Pearlin, 2004; Giusto & Van Willigen, 2003).

It is well documented that variation in the caregiver experience is common. For example, Mitrani et al. (2006) examined the role family functioning plays in the care process and found that family functioning mediates the relationship between burden and distress in family caregiving situations and supports the idea that family functioning contributes to the caregiver stress process. Successful family coping skills relate to improved family coping and care provision (Mitrani et al., 2006). Goodman, Zarit and Steiner (1997) identified personal orientation, an individual's self-evaluation or self-perception, as a predictor of caregiver strain and also explained how caregiving occurs in the context of wider family involvement (Goodman, Zahit, & Steiner, 1997). Not only does family functioning affect care delivery, individual caregiver differences can also be attributed to differences in providing care, which will be discussed in detail.

Gender Differences in Providing Care

In 1987, as researchers began looking at the specific relationship between patients and their caregivers, both male and female, potential differences in gender care traits emerged. Specific to MS care, research on gender differences is rather limited. Additionally, although information on gender differences of care in other types of illness is available, discrepancies exist regarding the role gender plays in caregiver strain. For example, Hirakawa et al. (2006) used the Zarit Caregiver Burden Interview to look at gender differences in care and concluded differences in caregiver burden may not exist between male and female caregivers in Japan. This study appears to be more the exception than the rule. Numerous other sources recognize gender differences and consider gender a significant variable in caregiver strain when caring for a failing elderly relative (Goodman et al., 1997; Horowitz, 1985; Pearlin et al., 1990; Stone et al., 1987; Young & Kahana, 1989).

In his landmark study discussed earlier, Pearlin (1990) reported the caregiver experience is influenced by key characteristics of the individual caregiver including: gender, age, ethnicity, education, occupation, social status, and financial status.

Other research discusses gender differences among informal care relationships and indicates informal caregiving was provided predominantly by women over 65 years of age (Stone et al., 1987). The authors also acknowledge that women face additional responsibilities in relationship to traditional roles that contribute to and increase caregiving strain. For example, women caregivers are more likely to maintain a balance between work and home schedules than their male counterparts. Competing demands, responsibilities and time constraints were additional stresses for the caregivers.

Research on providing care for an elderly, frail parent found that sons tend to provide care if a female caregiver is unavailable and are more likely to rely on their own female spouse to provide care for an ailing parent than provide care directly. This research additionally reported that sons provide less overall care and fewer hands-on services as opposed to female caregivers, and that females are more likely to be primary caregivers and provide routine hands-on care such as personal care and daily assistance.

Horowitz further acknowledged that caregiving is more stressful for women/daughters than men/sons (Horowitz, 1985).

Other research that examined gender-specific care provided to frail elderly spouses and parents suggested that particular characteristics of caregivers influence how a patient responds to treatment and illness. For example, the process of providing care may differ when gender and relationship of care dyads are considered. The research also suggested the kinship of the caregiver affects the caregiving relationship whereas caring for a spouse is different than caring for a parent (Young & Kahana, 1989).

Other research has focused solely on personal orientation as a predictor of caregiver strain and discussed personal orientation as feelings of competence, obligation, guilt and reciprocity or more broadly explained as an individual's self-evaluation or self-perception in a social context. A logical connection can be made that gender identification would impact many aspects of an individual's personal orientation (Goodman et al., 1997).

Gender Differences in Multiple Sclerosis Care

The few studies on gender differences as they specifically relate to MS have shown mixed results (Boeije & Van Doorne-Huiskes, 2003; Ybema, Kuijer, Hagedoorn, & Buunk, 2002). Ybema et al. (2002) showed no gender differences in relationship to caregiver strain. They suggested that perceptions of inequity are more important in understanding the caregiving relationship between caregivers and MS patients. Ybema and colleagues report "perceptions of inequality fully mediate the relationship between marital quality and emotional exhaustion, thus clarifying the psychological process through which quality of the relationship between caregiver and ill partner influences the emotional caregiver burden" (p.86). Both male and female caregivers experienced emotional exhaustion and depersonalization in the caregiving relationship. Study results were unaffected by controlling for a gender variable (Ybema et al., 2002).

In contrast, Boeije and Van Doorne-Huiskes (2003) identified gender differences in care as it relates to spouses with MS. They found that care given to a disabled spouse resulted in a sense of duty for caregivers which varied between males and females. The male reaction in the study was "characterized by the perception *you have to be satisfied with it*, feel obliged to give care and then become resigned to it." (p.238) The female reaction in the study was, "*I have to become harder and less self-sacrificing* as opposed to men, who do not feel compensated for the care they provide and they suffer for the burden ensuing from it" (p. 238). The caregiver burden was experienced as more intense by women than by men, which resulted from the different responses to providing care.

Social Support and MS Care

Numerous researchers have suggested that social support for patients with MS plays an important role in the well-being of the patient. In the late 1980's, professionals and researchers were concerned that MS imposed a significant emotional burden on patients and families. However, because there was little research to support this assumption, Devins and Seland (1987) reviewed the existing literature and identified the emotional impact of MS caregiving as one area for future research. They reported:

> The situation faced by MS patients and by members of their families offers a unique opportunity for the acquisition of new insights and useful data regarding the psychosocial impact of chronic disabling illness, in general, and the ways in which people respond to these adaptively and maladaptively. (p. 373)

Their review highlighted a need for research concerning adjustment and the emotional impact on the marital relationship in couples where one partner experiences MS. Couples and families as support systems were affected by the MS, and Devins and Seland acknowledged that others were beginning to examine the phenomena under a general social system lens (Devins & Seland, 1987).

Long and Miller (1991) also found that social support provided by families was significant to the well-being of MS patients. They reported that social support was a major factor in adapting to physical illness and noted that lack of family support is useful in predicting a tendency toward suicidal behavior in MS patients. In addition, the authors indicated that "further delineation of families' coping mechanisms, reactions of the family members to people with multiple sclerosis, and inspiration of hope within the family is needed" (Long & Miller, 1991). Long and Miller clearly identified the family as an area for investigation in the arena of social support and needs assessment, represents another disability study looking at the patient's support system in a care situation from a social model perspective.

Hakim et al. (2000) also examined the effects of MS on families and social roles and concluded that "MS has a profound impact on the patients' social roles and their relatives' well-being" (p. 288). The authors noted severe disability and cognitive impairment were associated with a negative impact on patients and families and encouraged community organizations to offer assistance to patients and families to reduce social isolation (Hakim et al., 2000).

Caregiver strain and stress continue to be the focus of research in the 21st century. For example, Chipchase and Lincoln (2001) examined the perception of strain, noting that caregivers were likely to be a life partner or spouse because of the age of onset of the disease. Caregivers reported various concerns about the caregiving role including home confinement; financial concerns; physical strain; and feelings of exhaustion, anxiety and future pessimism. Furthermore, the authors determined that caregiver strain was strongly associated with memory problems in patients with MS (Chipchase & Lincoln, 2001).

Rivera-Navarro et al. (2003) note that the burden of informal caregiving and support for disabled persons has received attention but little information exists on caregiving for MS patients. They described a specific profile of caregivers for MS patients with a high percent of caregivers being female parents. Additionally, this study looked at resources used by caregivers. The authors focused on increasing the knowledge base on MS caregivers and recommended that social services be made available to both MS patients and caregivers alike (Rivera-Navarro, Manual Mores-Gonzalez, & Bento-Leons, 2003). O'Hara (2004) examined the nature of informal care and professional care in MS patients in an effort to identify the incidences and frequencies of caregiving by family members as informal caregivers. The caregivers in this study rated assistance as being given more frequently than did the patients with MS (O'Hara, De Souza, & Ide, 2004). These perception differences between caregivers and patients are of interest in the present study and I will explore what role gender may play in shaping these perceptions.

As advances in medication management occur, a new generation of MS patients has emerged. Schwartz and Frohner (2005) state, "The existence of therapy for a disease that was previously considered unpredictably degenerative with no treatment is encouraging." (p.207) The current generation of patients is encouraged to continue life and family and expected to function with less disability for longer periods of time. As patient care and outcomes improve among individuals with MS, informal in-home care will increasingly be utilized. Schwartz and Frohner's finding that individuals with lower levels of social support--including family support-- had a reduced quality of life reinforces the importance of supporting family caregivers in order to improve quality of life for patients.

Caregivers and care receivers may or may not experience the care situation similarly. For example, using Margaret Urban Walker's expressive-collaborative view of morality as a theoretical framework, Abma et al. (2005) described a conflicting story of expectations and responsibilities between patients and paid caregivers and found the discrepancy between caregiver and patient reports was similar to conceptual differences experienced among nonprofessional caregivers. In contrast to the Abma et al. study, Pakenham's work (1998) focused on couple congruence in adjustment to multiple sclerosis care receiver-carer dyads and concluded that assisting the patient and caregiver to cope with the stress of the illness as a dyad results in more effective treatment. Pakenham stated, "…findings support the utility of both the coping congruence and average level of couple coping concepts in explaining collective and individual adjustment in care receiver-carer dyads"(p. 275). King and Arnett (2005) furthered the concept of couple coping congruence by reporting that couples who report higher levels of depression experienced worse dyadic adjustment. Therefore, care perceptions may or may not be experienced similarly.

In summary, social support provided by families and significant others is important to the overall well-being of an individual suffering from multiple sclerosis as well as the caregiver. Utilizing a systems theory approach in looking at the relationship of care and dependency supports the connection and interdependence between caregiver and care receiver. There is, however, a discrepancy between perceptions and experiences of care between the caregivers and patients with respect to care, support and needs. Little qualitative research is available on the subject of perceptions of care and support needs of unpaid caregivers. Furthermore, a relationship connection develops within the care dyad as interdependent care, with the care giver and care receiver both potentially depending on each other for various care activities. Traditional feminist perspectives of care may or may not be altered in the context of MS where men oftentimes take on the role of caregiver.

Benefits to the Community

Unpaid-nonprofessional care benefits the community by reducing expenditures and offering social connections for the individual with MS. In terms of financial benefits, it is difficult to measure cost savings to the community by care that is provided by loved ones in the patient's own living environment. A comprehensive assessment of the costs associated with MS in the U.S. conducted by Whetten-Goldstein et al. in 1998 reported that "most of the cost of MS was borne by MS individuals, families, and friends even though 98% of the respondents had some form of health insurance" (p. 424). A major component of cost in MS relates to both earning loss and informal care (Whetten-Goldstein, Sloan, & Kulas, 1998). Providing in-home care reduces the dependency and cost on the system which may benefit the community. While the cost of in-home paid care varies greatly, the Bureau of Labor Statistics reported that in May, 2008, the median hourly wage of home care aides was $9.22 and about 1.7 million jobs were held by home care aids (2010).

In addition to financial rewards, Cummins (2001) described personal and social benefits to the individual with a disability as well as the economic benefits for society through the utilization of unpaid-nonprofessional carers. Not only do family caregivers provide the patient with a generally improved quality of life and quality of care, the community benefits financially through the use of free care provided by families, most often a wife or mother (Cummins, 2001).

Care Needs

Caregivers report unmet demands which negatively affect their ability to provide care for their loved one. Financial needs are also a concern along with understanding specific needs in the care of MS patients. Furthermore, support measures for the caregiver are also in need.

Caregivers are circumstantially placed in the role of caregiver and therefore could benefit from support. Buchanan et al. (2009) reported that over half of those providing informal care to MS patients need help finding time for themselves and nearly half need help managing emotions and physical stress (Buchanan, Radin, Chakravorty, & Tyry, 2009).

Sato, Ricks, and Watkins (1996) studied the needs of caregivers of patients with MS. The respondents reported their physiological and self-concept needs were being met but identified needs in performing roles and responsibilities. The researchers suggested conducting in-depth interviews with caregivers while observing daily activities to deepen the knowledge base of caregivers as support systems and identify caregiver needs. Individuals who provide care are in need of relief from caregiving duties and could benefit from assistance in performing role functions and life responsibilities, for example, information sharing, advice giving and receiving and the provision of appropriate services to succeed in their role. Sato et al. also identified the need for caregivers to establish and maintain a connection with social services. Therefore, community support would benefit caregivers of MS patients. Participation in a community support group is an excellent way to deliver needed support and information to the caregivers of MS patients (Sato, Ricks, & Watkins, 1996).

Nodder et al. (2000) explored the care needs of MS patients and identified the need for coordination of services associated with the illness, family support and community support. They acknowledged that MS is a condition where the treatment and interventions impact the lifestyle of not only the patient but the family as well.

Costs of MS

MS is a costly disease to manage and many of the costs are private in nature. The earnings lost, the cost of diagnosis and treatment, and the cost to the family are extremely burdensome. A family may suffer huge financial loss over the course of the disease and community connections to assist the patient and the family are needed (Nodder et al., 2000). Whetten-Goldstein (1998) estimated that the annual cost of MS was over $34,000 per person with a conservative total lifetime cost per case of over $2 million. The major components of cost were earnings loss and informal care. At that time, health insurance covered about 51% of costs for services excluding informal care (Whetten-Goldstein et al., 1998).

These cost estimates do not account for recent advances in MS medication. The cost of medication management has increased tremendously in recent years, thus increasing the need for community assistance and linkage. With the recent addition of self-injectable MS drugs, the cost of care has increased over 35% per patient from $9,515 per patient in 1995 to $12,879 per patient in 2004 and 64.8% of that cost is attributed to prescription drugs (Kunze, Gunderson, Gleason, Heaton, & Johnson, 2007). The current cost of MS care is being studied with an examination toward cost-effectiveness in more recent publications (Noyes et al., 2011). Disease-modifying therapies in the United States can cost upwards of $48,000 annually (Goodman, 2012). This has contributed to the ongoing discussion about health care cost in the United States.

Other articles discuss the cost of MS in other nations; however, their cost is lower than the cost in the United States so transferring this into US dollars is not reasonable. These other nations have some form of national health care; therefore, their costs are lower than in the U.S. (Russo et al., 2004). National Multiple Sclerosis Society supports an overhaul of the U.S. health care system and providing health care cost assistance to individuals with MS. Recent estimates by the NMSS put the cost of MS, in 2007 dollars, at approximately $70,000 annually (Krishnan, 2009).

Other Illnesses

Caregiving has been examined within the context of a variety of illnesses including AIDS, dementia, Parkinson’s disease, Alzheimer’s disease, mental illness, and cancer. Similarities exist in caregiver strain, stress and support needs. However, differences exist in the particulars of the illness, too. Caring for an elderly person with a significant illness differs from caring for a middle aged person with multiple sclerosis. Care responsibilities and family burdens vary with each illness as well. MS symptoms and severity vary greatly, so uncertainty becomes a part of the experience. MS develops at the time when individuals are in the prime of their life, raising families and building careers. MS interrupts the usual life course, which can result in emotional difficulties for the patient and family. In examining the concepts of care in illness, the common theme among caregiver needs for all illnesses is social support. Social support is beneficial to both the care receiver and the caregiver and provides stress buffering properties (Monahan & Hooker, 1997). Support measures could reduce strain when utilized by caregivers. For example, research on caregivers of stroke patients found that the potential for future caregiver strain could be identified and that support measures, such as support groups, respite care, education, resource management, financial information and identification of resources, could be enacted in a timelier manner (Blake, Lincoln, & Clarke, 2003).

Caregiver Benefits

Pakenham (2005) reported that caregivers of MS patients experience multiple benefits in caring for a loved one with MS, despite the chronic sorrow often associated with providing care. Personal growth, greater insight, caregiving gains, strengthening the relationship, appreciation, health gains, and a change in priorities were all reported in relation to providing care. Furthermore, Pakenham reports that dyadic intervention approaches are more effective at providing support to the caregiver/care receiver dyad than supporting members of the dyad separately.

Patients with MS displayed a positive correlation between social support and quality of life measures. Social support had a significant contribution to the Quality of Life (QOL) measure. Indeed, people who perceived having more social support reported better overall mental health (Schwartz & Frohner, 2005). Suicidal tendency in patients with MS has also been affected by decreases in relationships that exhibited family support. Long and Miller (1991) noted that an innate function of being a care provider is to benefit the one needing care and that social support improves quality of life measures and decreases suicidal tendencies. Their study found that although there were complex factors involved, family support was most useful in predicting suicidal tendency in people with MS.

Summary of the Literature Review

Given the researchers' interest in the subject of MS and non-professional caregivers, the article by Fine and Glendinning (2005) became the starting point of this dissertation by linking care and dependency to a feminist theory of care and a social construction of dependency. The ethics of care theory was examined by looking at such scholars as Gilliagan, Held, Noddings, and Tronto. This in turn lent itself to understanding the concepts of general caregiving and examining the works of Pearlin (1990) in his Stress Process Model. Goodman, Zahit, and Steiner (1997) additionally described personal orientation as a factor in caregiver strain.

Boeije and Van Doorne-Huiskes (2003) focused specifically on gender differences as they relate to MS caregiver strain, and Devins and Seland (1987) identified the need for future research in the area of providing support to MS caregivers. Long and Miller (1991); Sato, Ricks, and Watkins (1996); and Hakim et al. (2000) offered valuable insights in the provision of care to MS patients. Most recently, Schwartz and Frohner (2005) and Pakenham (2005) addressed the importance of informal care with a new generation of MS caregivers and discussed the need for future research in the area of unpaid-nonprofessional care of MS patients. This literature review discussed the nature of caregiving and how caregivers experience this stressful situation. That relationship for MS patients needs to be examined in more detail because it is an underdeveloped area of knowledge, and a qualitative study will provide an opportunity to develop the concepts of care and dependency for this illness while allowing both the care provider and care recipient to co-construct the experience.

Pyramid of Care

In looking at the integration of theories for this research, Figure 2: Pyramid of Care, is helpful is creating a visual representation. The **social model of disability** is the starting point in understanding that society has responsibility in creating an environment hospitable to the disabled individual. Disability has a particular social meaning which implies need, care, accommodation and adaptation. **Pearlin's Stress Process Model** helps to understand and explore differences in the care experience with particular attention to the role that **gender** as well as other life factors play in understanding the experience of giving (care) and receiving care (dependency). A deeper understanding is

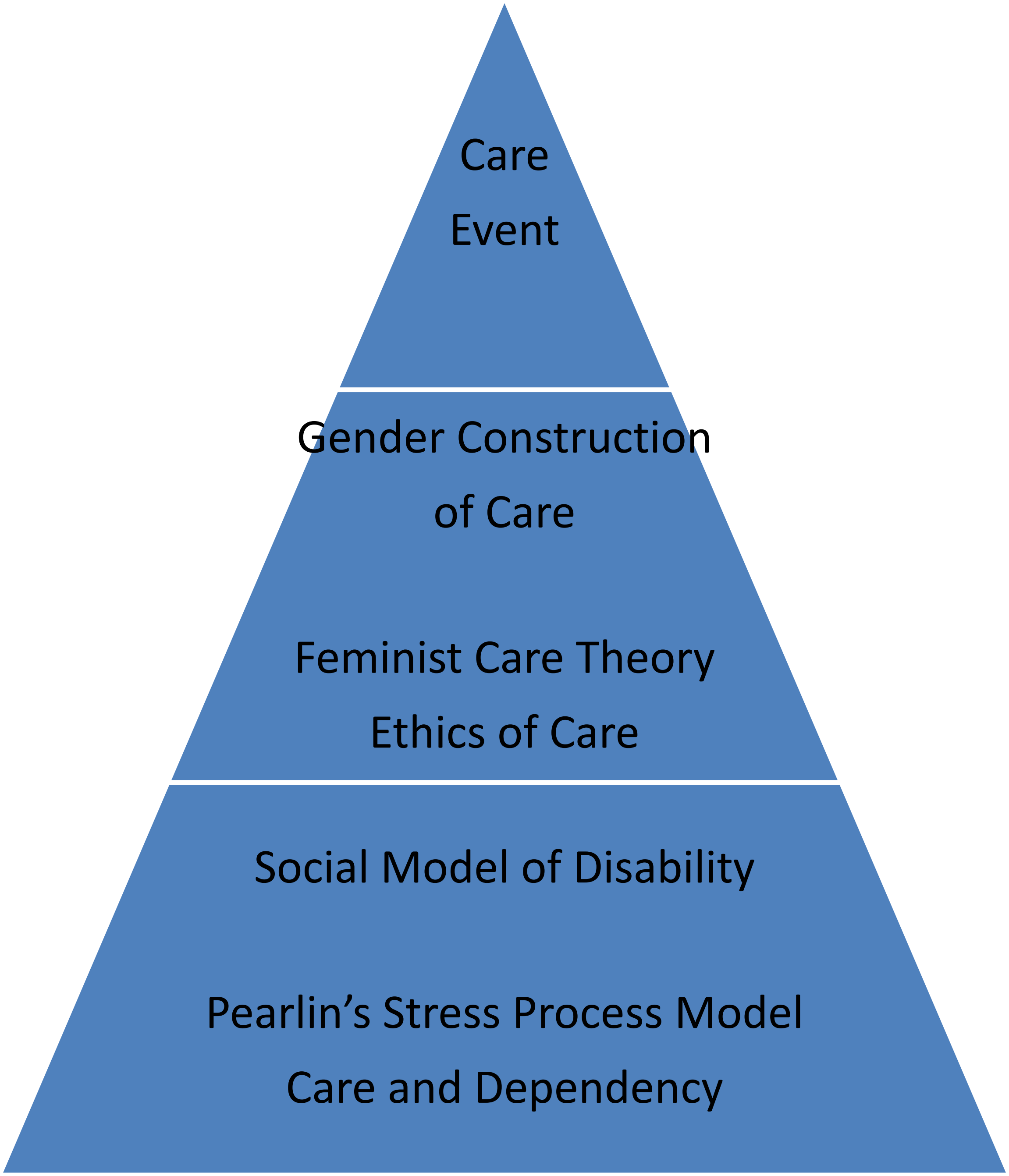

Figure 2: Pyramid of Care

provided by using **gender construction theory.** This framework is useful to evaluate behaviors necessary for disability care which fall outside traditional gender expectations. F**eminist care theory/ethics of care** assists the research in understanding that providing care is a natural life expectation and activity typically assigned to women. People are defined by their behaviors. Therefore the **care event** is the pinnacle to understand the gendered experience of care in this research. Behaviors outside of society's normal gender construct result in a source of personal conflict for both care givers and care receivers.

CHAPTER 3

METHODOLOGY

Introduction

In Chapter Three, I reflect on my personal experiences as a caregiver to my husband who has MS and how my unique perspective allowed me access into the participant's experience. My intent was to use my experience as an advantage in connecting with the participants, which allowed a rich, deep expression by the participants. Connecting with the participants potentially allowed for greater sharing. Additionally, in this chapter, I explore the nature of the constructivist research paradigm and how this research design helped me develop a co-constructed reality of the perceptions of care with both the caregivers and care receivers. The research design is outlined, with attention to Institutional Review Board approval, sampling, convenience, data collection, interview schedule, data analysis and study strengths and limitations.

Personal Perspective

My interest in unpaid-nonprofessional caregiving for patients with multiple sclerosis developed out of my personal experience because my husband has MS and I too am an unpaid-nonprofessional caregiver. My research questions arose from my general interest in the subject of MS and moved to a specific focus on caregivers as I conducted initial steps in my literature review. I became interested in articles that focused on the caregiving experience and from there I noticed a gap in the existing research. Although research on general care and caring for patients with other illnesses was available, research focused on MS caregivers' experiences was generally lacking. Therefore my questions for this research arose directly from my personal experience and my review of the literature.

MS has been a part of my life for 18 years. I felt as if others had more understanding and responsibility to the disease and generally thought my husband's illness was well contained. I felt we coped with the situation quite well. I know now that caregivers and patients learn to adapt to the challenges using a variety of available resources. I also understand that gender is a factor in this situation for both caregivers and patients, however; it is one of many factors that contribute to patient and caregiver outcomes.

My use of self in this research study is of particular importance in that I too can relate and on some level understand unpaid-nonprofessional care experiences. My husband, John, a board certified internal medicine physician and a licensed pharmacist, has multiple sclerosis. MS has been a part of our lives for over 18 years. John received his diagnosis in November of 1993 following our engagement. We married the following March and life proceeded. MS episodes occurred several times, making unplanned, random visits that changed our life plans. During our fourth pregnancy, John suffered his most significant exacerbation, extensive vision impairment in his left eye, which resulted in total loss of vision in that eye. During previous episodes of MS, John had vision problems that left him with central vision loss in his right eye. The lack of vision was extensive and required him to leave his work as an emergency room physician. John was unable to complete a variety of tasks required of a primary care physician and he spent 3 years at home on disability. It was during that time that I was able to return to the University of Utah and pursue my Ph.D. studies in social work.

I have a special connection with spouses and caregivers of individuals with MS. I personally understand the random attacks that strike when no one is watching. I live the experience of compartmentalizing MS, tucking the disease away in a box to live life and take care of my family until the disease rips from the box and shows itself in such a bold manner it attacks the flow of our family where we must stop and respect the power of the disease. At any moment the courses of our lives may change and we are forced to proceed in a new direction as the MS demands. One day we are preparing for the birth of a fourth child and the next my husband has gone blind. Another moment we are at a party when my husband excuses himself and collapses in the bathroom with intense vertigo. We recover, we move on, we forget and it strikes once more. I feel powerless to the disease and I hate the loss of control that is a part of this situation. My coping with the disease resulted in my deciding to turn a difficult situation into an opportunity to complete my Ph.D. and achieve a long desired goal. My husband's time off work allowed me the support and opportunity to work on my studies. A person very close to me suggested that I must be happy that my husband lost his eyesight because it allowed me the opportunity to work towards my Ph.D., I told that person that I would never be happy that my husband lost his eyesight, but that I could truly understand that sometimes people find the strength to make something good come out of something bad. When I began thinking about possible research topics, it seemed fitting to focus my research on multiple sclerosis and the unpaid-nonprofessional caregivers who share some of my experience. John started back to work in July of 2008 as a professor of medicine at Wright State University where his vision is not needed nor required. He is director of the residency clinic and he supervises medical residents providing treatment in a free clinic setting. Wright State University is a leader in providing necessary accommodations to assist people with disabilities to return to employment.

I struggled with whether to share my personal experience with the participants in my research, and after much thought and deliberation and a review of relevant research, I decided to do so. Padgett (2008) discussed studying the familiar versus the unfamiliar and identified two advantages of remaining with the familiar in a qualitative research study. The first advantage is developing rapport with the participants. The second is providing a jump start in knowledge acquisition. Padgett also notes that a disadvantage is the risk of being too close to the subject matter. Knowing too much about a subject can create blinders and lead to prematurely assuming the answers (Padgett, 2008). Examples of outstanding qualitative studies conducted by researchers with a close personal connection include research conducted by Irving Zola on disability (Zola, 1983), Catherine Riessman on divorce (Riessman, 1990) and Arlie Hochschild on working parents (Hochschild & Machung, 1989). Anthropologist Robert Murphy suffered from a neurological condition that gradually restricted his movement and resulted in his death. He made tremendous contributions to disability studies with his work, *The Body Silent*. Toward the end of his life, he used his “own intimate experience of disability and his intellectual acumen as an anthropologist to broaden our understanding of human behavior (Goldin & Scheer, 1995; Murphy, 1990)

I believed the use of my close personal connections would provide transparency by allowing the participants a connection to the researcher and elicit a shared experience among participants. It is my understanding that being an insider to this disease will foster and encourage participants to feel comfortable sharing their experiences with an individual who has shared some of the same burdens. It is important to note that my husband's experience with MS is not nearly as devastating as other's experiences. John has a strain of MS that has not been as progressive or as debilitating as other people typically experience. His MS has attacked his vision significantly, but he remains able to walk, move and meet the demands of daily living with minimal assistance. Many others with MS are not as fortunate and there are others who experience fewer symptoms than my husband. No experience of MS is typical.

There are risks and concerns of sharing this information with participants. The most probable challenge of sharing this information was that the participants could assume a shared understanding and choose to not offer as complete an explanation to the phenomena being studied. I was willing to answer questions the participant had about my experience with MS, although I used my clinical skills to bring the discussion back to the participant's experience. My goal was to make the participant feel comfortable in the interview with myself as the interviewer while bringing the discussion back to the interviewee. I exerted limits with the participants and professional boundaries within the interview if the participant becomes overly concerned with my experience. I specifically told participants that I was not there to talk about my situation, but rather that I was interested in hearing about their experience for the research. I remained cognizant of this potential complication and stayed reminded to probe more deeply in order to develop rich explanations. My role as a clinical social worker for 14 years undoubtedly assisted me in conducting my research interviews and developing understanding of the participant's experience. I was able to use my clinical skills to direct the focus back to the participant and encourage a deep exploration.

In order for me to adequately process this experience, I kept a self-reflective journal. I used this journal writing during my time as an interviewer to help ground myself in the research, and I was able to reflect back on my journal notes as I analyzed the data. I was aware that I was not the center of the research inquiry although my prior experience brought a richness and depth to the situation. I was careful not to assume understanding; rather, I used a third interview with both the caregiver and the care receiver to complete extensive member checking, and asked participants if the themes resonated with their experience. Finally, I offered participants the opportunity to review their interview transcripts for authenticity to provide additional member checking.

Personal Growth

Over the course of my research my, husband's symptoms have gotten worse. At times the interview conversations hit close to home, especially when I heard about similar physical limitations. Mostly the participants were provided with a connection to me as the researcher and forced me to process my own emotions surrounding this illness. I often left interviews with a range of emotions, from feeling overwhelmingly sad to inspiration. MS is isolating. Many people I spoke with did not know others with MS nor had they had much opportunity to speak with another patient or caregiver. With MS the mere act of living with the illness forces people to isolate.

Using self in research has been successfully conducted by other researchers, including Zola, Riessman, Hochschild and Machung and Murphy as noted above. This was a decision I made early on in this process, and I believe it made for a richer experience. Having a husband with MS allowed for immersion in the field and a connection to the participants. At times the sadness of the stories was especially heartfelt and concerning to the researcher, and at other times the participants shared a deeper side of their experience. As a researcher I was able to use language the participants understood. Participants felt safe because we shared a specific connection to this situation. I understood the available medications and the delivery system because my husband has taken four of the differing types of medication. I understood patients when they talked about taking Tysabri ® (natalizumab), a monoclonal antibody that requires I.V. infusion every 28 days administered at a medical facility. I knew that Copaxone® (glatiramer acetate) requires self-injections daily, that Rebif® (interferon beta-1a) requires injections three times a week, and Avonex ® (interferon beta-1a) one time a week (MSLifeLines, 2012). Participants were interested in what medicine my husband took and how it was working. I am also familiar with the side effects of all the medications my husband takes. Side effects from interferon beta-1a medications were more difficult for my husband. He experienced flu-like symptoms after each injection that lasted until the time of the next injection. Participants asked if my husband experienced a particular symptom that they themselves experienced. I carefully reminded myself to not assume understanding but allowed the participants to direct the information and share their experience. When asked, I answered questions but I did not offer unsolicited information. I was able to share some knowledge of the illness and my personal experience if asked. Several participants asked questions, some did not.

Constructivist Research Paradigm

The purpose of this research was to explore, develop, and understand perceptions of care between care providers and caregivers of MS under the lens of feminist care theory/ethics of care within a social model of disability. In order to explore phenomena of care, gender differences in care and perceptions of care, qualitative research was utilized exclusively. Qualitative research seeks to develop and understand the dimensions of a phenomenon specifically as it relates to the human experience and the world. Qualitative research generates ideas and hypotheses by understanding that reality is understood through the constructs of individual experience. Qualitative research creates the space which allows the voice of the participants to be heard, developed, shared and understood within a context of developing commonalities among participants (Lincoln & Guba, 1985).

The research paradigm for this dissertation was a constructivist paradigm. The research examined perceptions of reality in the interaction of caregiver and care receiver dyads. This interaction was subjective. The nature of reality (ontology) for the project was constructivism, i.e., co-constructed realities between caregiver and care receiver. The nature of knowledge (epistemology) was interpretative and dialectical as interaction is subjective and shaped by values and experiences. This research sought contrasting and opposing viewpoints among the participants. The way of knowing (methodology) for this project was dialogue that is transactional and subjective. Knowledge was developed by interactions between individuals and among individuals. Knowledge was sought through dialogue with the participants (Lincoln & Guba, 1985).

Using a constructivist paradigm, the main research question (what is your perception of care?) was asked of male and female patients with multiple sclerosis and their male and female primary caregivers. The research sought to identify how the reality of care is being co-constructed by the caregiver and the patient with specific regard to gender perceptions. Knowledge from this research was developed by co-constructing the care experience. Both caregiver and patient views were necessary and significant to formulate understanding of the care experience. Both provided an understanding to the question of perception. One reality does not exist; rather, the perception of reality exists on both sides of receiving care and giving care. The epistemology considered that caregivers and patients may have contrasting views, and the research data were interpreted with the understanding that individuals' experiences may share multiple meanings. The data were interpreted by arriving at a synthesis of meaning; thus, the interpretation is dialectical in nature.

Furthermore, the research focused on understanding if traditional gender roles affect the care situation. Traditional gender identities are society's defined roles of acceptable and socially appropriate behavior that is attached to men and women based on their sex. Traditional gender roles depict women as caring and nurturing and men as aggressive and competitive. Were there gender differences in providing care and receiving care among patients with MS? Finally, the research explored caregiving under the lens of dependence, independence and/or interdependence in the relationships as discussed in Fine and Glendinning's work on care and dependency (2005).

Research Design

Research Questions

This qualitative research study explored the phenomena of the gender relationship in care for multiple sclerosis patients by addressing the following research questions:

1.) How do caregivers and those diagnosed with MS experience the caregiving relationship?

2.) Does gender influence the provision of care and perceptions of care in providing for patients with multiple sclerosis?

A secondary research interest of care needs and social support was additionally explored with the following research questions:

3.) What are the care needs of both the MS caregiver and care receiver?

4.) What is the role of social support in the care relationship?

I conducted 30 interviews with 10 couple dyads, 5 dyads with a female patient and 5 dyads with a male patient. Interviews with the caregiver and care receiver were conducted individually and a follow up interview with both the caregiver and receiver was also conducted. The follow-up interview was used to attempt to co-construct the care experience within the couple dyad.

Initially, the individual interview questions included queries that are specific to the caregiving responsibilities. The researcher asked both the caregiver and care receiver the following questions individually:

Interview Question Guide

Research Question: How do caregivers and those diagnosed with MS experience the caregiving relationship?

Interview Guide:

Tell your story of MS.

How would you rate the illness in terms of severity?

How did you deal with the initial diagnosis?

How did your caregiver deal with the initial diagnosis?

How does caregiving/receiving affect your relationship?

Tell me about the care you give/receive.

Research Question: Does gender influence the provision of care and perceptions of care in providing for patients with Multiple Sclerosis?

Interview Guide:

What is it like to be a man/woman with MS?

How do you care for each other?

How do you care for yourself?

How are you dependent on one another?

How are you independent from one another?

Research Question: What are the care needs of both the MS caregiver and care receiver?

Interview Guide:

How many hours of care are given/received during a day/week?

What types of care tasks are being provided by the caregiver?

How is the family unit involved in the care?

How would you rate you or your partner's care needs?

What is needed in terms of your caregiving/receiving?

What would assist you most in your role of caregiver/receiver?

What needs do you have that would assist you in the care relationship?

Research Question: What is the role of social support in the care relationship?

Interview Guide:

What are the other types of care the patient receives aside from the care provided by the primary caregiver?

How is the family unit involved in the care?

Describe any support you receive outside the primary family unit, both professional and nonprofessional.

3rd Interview Follow-up Questions:

This interview served as a time for clarification and provided the participants with an opportunity to member check. Individual participants received initial interview transcripts in the mail for review. Participants were asked if they wanted to change or clarify any part of the transcript. One couple exchanged transcripts and read their partner's interview. The remaining chose not to exchange. Several couples did not take advantage of this opportunity as a time to elaborate, referring back to the initial interview as "that's pretty much it," Others engaged in a conversation about their situation with one another. The third interviews primarily served the function of member checking and prolonged engagement.

Institutional Review Board

This research project was submitted and proposed to a dissertation committee chaired by Dr. Christina Gringeri for review. Following the committee's approval, application was made to the University of Utah's Institutional Review Board (IRB) and research approval was granted. Research occurred following all IRB guidelines. Neuroscience Research Center in Dayton, Ohio accepted University of Utah IRB approval and did not require additional IRB application or approval.

Sampling

Ten couples were recruited for this study. Each participant was interviewed individually, followed by a joint interview of the caregiver and care receiver, resulting in three interviews per couple dyad for a total of 30 interviews. Lincoln and Guba (1985) describe techniques used to establish and improve credibility: prolonged engagement, persistent observation and triangulation. Multiple interviews with each couple dyad provided prolonged engagement and helped establish credibility.

In order to achieve gender balance, five of the couple dyads had a male patient with MS and five couple dyads had a female patient with MS. The couples were selected from the patient population at Neurology Specialists in Dayton, Ohio. Neurology Specialists employs three neurologists and two research assistants and treats a large number of patients with MS from the greater Dayton area. Additionally, Neurology

Specialists houses the Neuroscience Research Center, which provided a convenient and familiar location for the interviews to occur. The research assistants from the Neuroscience Research Center assisted in sampling of potential interviewees for this research project.

The sample was a convenience sample. I was on location at the clinic to secure the 10 couple dyad participants. The participants were recruited with the assistance of three research assistants at Neurology Specialists. Research assistants approached all individual patients when they presented for their clinic appointment. Each patient received a flyer from the research assistant that explained the research and his /her potential participation and involvement. Patients who were interested in participating in the study met with the primary researcher to determine if they met the eligibility requirements, understood their scope of involvement and would agree to participate in all interviews. If both the care provider and patient were present, available and under no time constraints, the initial interviews occurred separately at that time and in the clinic setting. Patients without a care provider present were asked to inquire with their care provider and contact the researcher if both were interested in participation in the study. Interviews for those individuals were scheduled following subsequent contact from the participants. All interested participants were assigned a pseudonym and placed into subcategories of male or female patients or caregivers. Joint follow-up interviews were scheduled after the first round of interviews had been completed and transcribed.

Demographic information was gathered prior to the start of the interviews with the use of a questionnaire (Appendix A). Demographic information included gender, age, age of MS onset, relationship to caregiver, socioeconomic status, living situation, education level, available family and outside support, involvement in formal support services, employment, average hours worked, and additional family commitments.

Inclusion and exclusion criteria were kept simple to maintain the integrity of convenience sampling. At least one of the participants in the couple dyad had to have a diagnosis of MS to be included in the study. The second criterion was simple as well. In order to provide the gender differences needed to explore this phenomenon, five MS patients were female and five were male. It should be noted that individuals with significant impairment may have chosen not to participate in the study because of the stamina required to sit and talk for extended periods of time.

Convenience Sample

Although it is the least rigorous technique, convenience sampling or availability sampling is often appropriate for social work research, particularly when researchers are exploring a person-in-environment perspective of a particular set of social problems, which is the case is this study. The decision to use convenience sampling for this research is based on accessibility, ease, speed and cost savings. According to Weiss (1994), convenience sampling is a valuable technique that can provide important information for qualitative research.

The limitations of convenience samples include a reduction in scientific precision, limiting information and credibility (Marshall, 1996; Weiss, 1994). Sampling in this manner could potentially bias the research with research participants who are seeking medical care and thus are experiencing complications from the disease. Neurology Specialists and the Neuroscience Research Center provide a service of monthly medication appointments which helped reduce the potential sick sample bias. A number of patients at this clinic are present for a regularly scheduled IV infusion. Patients who receive this particular treatment must present at the clinic every 28 days for an infusion, regardless of health status. Including these patients, who are in the clinic for a routine medical visit rather than for a sick call, reduces the potential bias concern of a sicker patient sample.

Data Collection

Semi structured interviews were conducted with each care receiver and care provider. These individual interviews allowed the participants the opportunity to construct the experience of care and provide an opportunity for communication and exchange of dialogue between the participant and the researcher. A third interview was conducted with both members of the couple dyad present to provide an opportunity for the participants to co-construct the care experience. This interview allowed participants to review the transcripts and make necessary changes and provide member checking. Lincoln and Guba (1985) explain member checking as a critical technique for establishing credibility, and in this case it allowed for testing of the gathered information between the couple. Additionally, this final interview offered confirmability of the previously gathered information and further established credibility by allowing for a prolonged engagement and an additional opportunity to interact and gather information from the participants.

At the time of the each interview, participants were compensated with a $25 gift card from a local all-purpose store. Participants were made aware of the incentive prior to enrolling in the study. The gift card was a small token of my appreciation for their participation in the study and their willingness to share their stories with me.

Interviews

In-depth, individual, semi-structured interviews were conducted with the care provider and the care receiver and transcribed verbatim. A third interview was conducted with the dyad and transcribed. The interviews lasted 60 to 90 minutes and took place at Neurology Specialists, the Neuroscience Research Center or at another mutually agreed upon location. Both individuals in the dyad needed to agree to participation before starting the interview process. Some participants had difficulty with mobility so reasonable accommodations were made to reduce travel burden for the participants. Each participant answered detailed questions about caregiving and receiving, stress associated with illness, and stress associated with receiving care and providing care. Furthermore, perceptions of care were explored to surface gender differences between caregivers and care receivers as well as similarities.

Follow-up Interview

The third interview with both care partners allowed the researcher the opportunity to better understand the experience and provided the opportunity for member checking of participants' original statements. Ultimately, the third interview was used to gain a deeper understanding of the data and establish another opportunity to engage with the participants and observe their interactions as a couple. No serious disagreement occurred in the third interview although minor disagreement was handled by careful representation of each participant's individual expression through member checking where I specifically acknowledged the disagreement. Prolonged engagement and persistent observation with the participants helped to establish credibility, and the constructivist research paradigm was developed in more detail at the third interview. Both care partners were encouraged to discuss and exchange ideas about their care situation, and participants provided feedback concerning this shared experience. Members both agreed and disagreed with the comments made by their partner. During the third interview, participants were encouraged to develop a co-constructed reality of the experience that mutually described their experience.

The third and final interview took place at a separate time and location, which allowed for a triangulation of sources by examining the information at different points in time. Additionally, having 10 separate dyads to interview provided rich content of sources by allowing for comparison of people with different viewpoints.

I thought the follow-up interview with the couple would be especially beneficial in this process, but participants were more comfortable speaking alone about the situation as opposed to speaking about the illness in front of their partner. Individual interviews were more elaborate as opposed to joint interviews. It felt as if participants had shared their story with me and did not really have more to say at the joint interview. I tried to elicit a deeper understanding, but at times I was met with short answers or looks toward partners to see if they would respond. I respected the nonverbal clues and allowed the participants to share what they wanted. My thought was to provide prolonged contact with the participants to enrich the information, but I am not sure if much additional information was gained by the joint interview process, especially because some participants chose the coping technique of denial and tried not to speak of MS with their care partner. Several of these interviews felt forced for the participants. One joint interview did yield a discussion about perception differences. In that interview the participants allowed one another to read their transcripts, which facilitated the discussion. I let participants decide if they wanted to share their individual transcripts with their partners. Each individual transcript was mailed to each participant individually. I am not sure how many allowed their partners to read them or how many read them themselves. In one case a male caregiver may have been illiterate.

Data Analysis

All interviews were audio taped and transcribed verbatim. The qualitative research computer program, N Vivo, was utilized for purposes of coding, data management, gathering themes, and evaluation. Participants were presented with a copy of the transcripts and given the opportunity to change or clarify answers. I completed NVivo training in the summer of 2010 and developed understanding of the computer program and additional insight into processing the information.

I compiled and presented the demographic information of the research participants in a table and paid particular attention to providing anonymity for the participants. As already noted, participants were given pseudonyms which were used in the reporting of results.

Following each interview, the researcher processed the experience through journaling where significant ideas, themes and thoughts were recorded. Upon completion of the interviews, raw data, process notes and analysis summaries were examined by the researcher. Emerging themes were developed. The experiences were discussed in detailed description as a way to achieve transferability. Care was taken to describe the phenomenon in detail as shared perceptions emerged.

The third interview with the dyad provided an opportunity to help me interpret data—that is, how the dyad themselves interpreted their original interviews. My hope was that the third interview would help develop accurate understandings of the experience with the assistance of the dyads interpretations.

Interviews were than transcribed and coded using NVivo software. Themes were coded directly from the transcripts as opposed to listing the themes and looking for statements to fit. The interview transcripts guided the findings. After all interviews were coded; the researcher returned to the identified themes and developed the chart of how frequently ideas were discussed in the interviews.

I decided to let the participants' interviews guide the development of my connection points, or as termed in NVivo, "nodes". There were a few nodes that had only one source and reference. There are others that were discussed in as many as 21 of the 29interviews. I used NVivo to highlight text and link those similar items. I then relied on more traditional methods of converting those nodes into a printed document. I color coded the documents by gender and went through every theme looking for gender connections and patient and caregiver connections. Writing became a way to weave the connections and share the participants words, some awkward some eloquent.

Strengths and Limitations of Study Design

Using this particular study design helped describe the complex situation of giving and receiving care for MS patients under a feminist care theory perspective and allowed for an understanding and description of an individual's personal experience. This allowed the researcher to develop an understanding into the phenomenon of care in MS and develop a reality that was co-constructed and derived from the participants' own perceptions and experiences, and the meanings they attribute to both.

The researcher was granted access to a mid-size neurology clinic population, therefore, strength of the research is that a convenience sample using inclusion and exclusion criteria provided a purposive sample from the population as opposed to other types of sampling procedures. This type of sampling is not purely convenience sampling because the participants were chosen based on gender and illness not just who came to the clinic. This allowed for a concentration on issues of gender and excluded other factors such as race. Having access to a large number of individuals with MS provided a generous sample size for this research. This large population was reduced to the desired so the researcher could describe cases in detail and provide individual case information.

Personal experience with MS may be both a strength and limitation to this particular design. As I carefully kept in mind that I was not the center of the research, my intent was to use myself to bring a richness and depth to the situation. Self-reflection and journaling provided an opportunity to explore the use of self freely. The strength of my experience allowed me to gain wider access to information in order to co-construct the reality of this particular social situation. Results of qualitative research are open to the researcher's personal biases; therefore, member checking was an important and deliberate part of the research process.

Other limitations of the study design are the time constraints required to interview and process the information. In-depth interviews require sufficient time and individuals with this disability may not have the physical capacities to endure long periods of sitting and talking. Those individuals may have self-selected out from participation in the study. Additionally external validity is limited and the results may not be generalized to other people in other settings.

Learning Process

In this process, I learned from the literature review, the research design and the conceptualization of this research. Mostly, I learned from the participants. Strangers allowed me into their life situation, answered my questions and shared their stories. The participants were gracious, kind and informative. I was able to use the transcribed interviews with the help of NVivo software to make connections and develop themes among the participants. I read each and every transcript and coded after reading a particular idea or theme. I was somewhat overwhelmed with the volume of information that took several months to obtain. I did not have preconceived ideas of what I was attempting to find.

Pearlin's Stress Process Model offered a framework for understanding the entirety of the caregiving situation, including the individual differences that each couple brought to the situation. The model was utilized in discussing the caregiving situation for families with MS and will be further discussed in Chapter Five. Two additional sources arose through the course of the interviews and processing stages, Kübler-Ross stages of grief and Zusne and Jones concept of magical thinking will both be discussed in Chapter Five. Specifically, Kübler-Ross' stages of grief helped explain the emotional processing that is a part of surviving MS and MS caregiving. People go through various stages in processing and those stages correlate with the stages of grief and loss. Zusne and Jones magical thinking concept further explains bargaining and acceptance. (Kübler-Ross, 1969; Pearlin et al., 1990; Zusne & Jones 1989)

CHAPTER 4

RESULTS

Introduction

Gender does affect the MS caregiving experience, just maybe not the ways I originally thought. I intended to prove that caregivers and patients would connect themselves to certain tasks. Those responsibilities would associate with traditional gender roles and participants would utilize available resources in taking care of responsibilities. What I found is that not everyone has access to resources and availability to certain resources. Use and availability of time, people and finances are a part of understanding the entire care dynamic. Gender plays a significant part in understanding the care dynamic in that gender shapes perspective and understanding of MS within the social constructs of gender. Gender is the lens through which both the caregiver and care receiver view the many tasks and responsibilities associated with MS. Deviation from role expectation is a point of awareness for many caregivers and care receivers alike.

Interview Coding

Throughout this chapter, participants' own words are used to illustrate their perceptions and experience. Pseudonyms and numbering are utilized to help readers identify participants' roles and relationships. All female patients are given a pseudonym and numbering code (FP#). Similarly, male caregivers are coded (MC#), male patients (MP#) and finally female caregivers (FC#). Numbers equally correspond so that male patient 1(BOB MP1) and female caregiver 1 (MARY FC1) are connected-related as a dyad.

Overview

Unpaid-nonprofessional caregivers of MS patients are responsible for a wide variety of care activities and responsibilities. The care situation can both positively or negatively affect the outcome for the patient. That care relationship is the focus of this study. Considerable amounts of care provided to people with MS are informal in nature, and most patients want to receive care in a familiar environment. There are numerous benefits to both society and the MS patient in utilizing unpaid-nonprofessional care. Specifically, unpaid-nonprofessional care is care provided by loved ones, usually family members. Health care providers recognize the psychological and social advantages of utilizing informal care (Carton et al., 2000). The care provider can be burdened with the many needs of the MS patient. Focusing on the caregiver and care receiver in this experience is the center of this research.

The research study was informed by a social model of disability perspective and a feminist care theory, specifically, the ethics of care. The study further encompassed gender and other factors, with reliance on Pearlin's Stress Process Model. Further, care and dependency were considered. While conducting the research interviews, two additional theories emerged and are relevant to this work. Participants spoke of their experience in terms of loss and appeared to be grieving the loss of ability. Therefore, Kübler-Ross's stages of loss and Zusne and Jones' concept of magical thinking are discussed in connection with the MS care experience. The research explores how gender differences contribute to the care experience and are critical to understanding the MS care phenomenon. Finally, the research explores care from both a care receiver and care provider perspective.

To explore these phenomena, 29 interviews were conducted with patients and caregivers alike. Twenty individuals were interviewed individually, five males with MS and their spouses and five females with MS and their spouses. Nine of the ten couples completed a joint follow up interview. Interviews were conducted at Neurology Specialist, the Neuroscience Research Center or in the participant's home depending on the participant's desire and availability. Participants were made aware of the study by flyers at the clinic and agreed to participate in the interview process. Participants were all from the greater Dayton, Ohio region and had various levels of illness severity. Interviews were taped, transcribed and analyzed using NVivo software.

Demographic Information

As this is a relatively small study, demographics are being reported as a means to understand this particular research population. Inference about causality and connection are not being made; rather, demographics are merely being reported. Understandably, demographics would change with different participants. Demographics contribute to Pearlin's discussion of the background and context affecting the overall care situation. Some are primary stressors and adversely affect outcome for participants. Therefore, demographics are being reported for: age, race, and household composition, age of onset, education level, household economic status, and employment status. Certain situations such as joblessness may affect the entire environment for participants and may also help or hinder life function.

For this group, caregivers ranged in age from 32 to 58 years with the average age being 48.7 years. Patients ranged in age from 41 to 59 years with the average age being 48.9 years. All participants were Caucasian. Three of the couples lived by themselves. Two couples lived with one child, four couples lived with two children and one couple lived with four children. MS was diagnosed for the participants as early as age 19 and as late as age 46 with the average age of diagnosis being age 33. Education level varied for caregivers and patients (see Figure 3).

Gender did alter the education level specifics. Figure 4 further breaks down the education level of patients and caregivers by gender (see Figure 4).

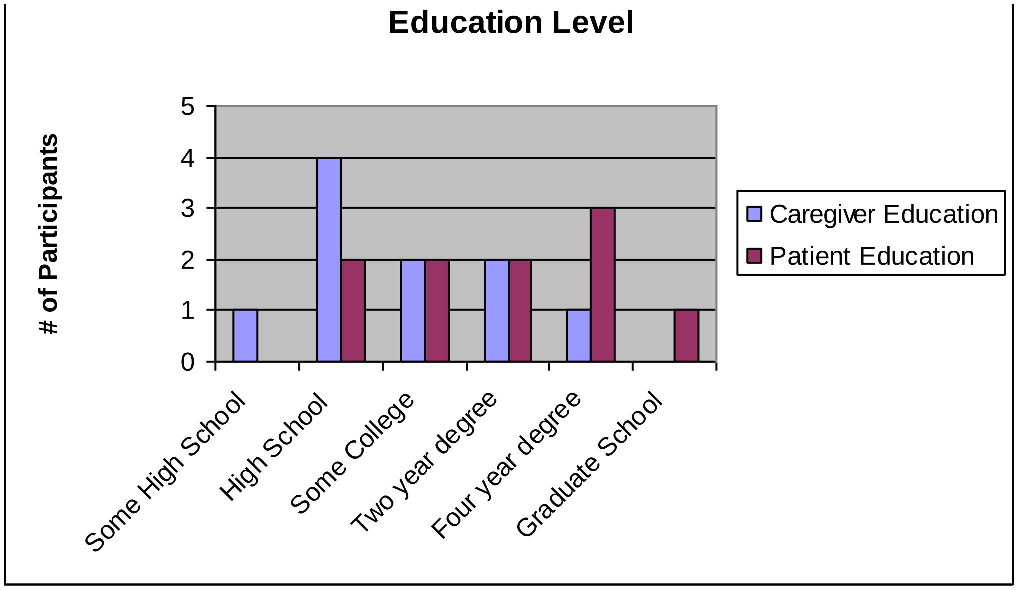

Figure 3: Caregiver versus patient education level

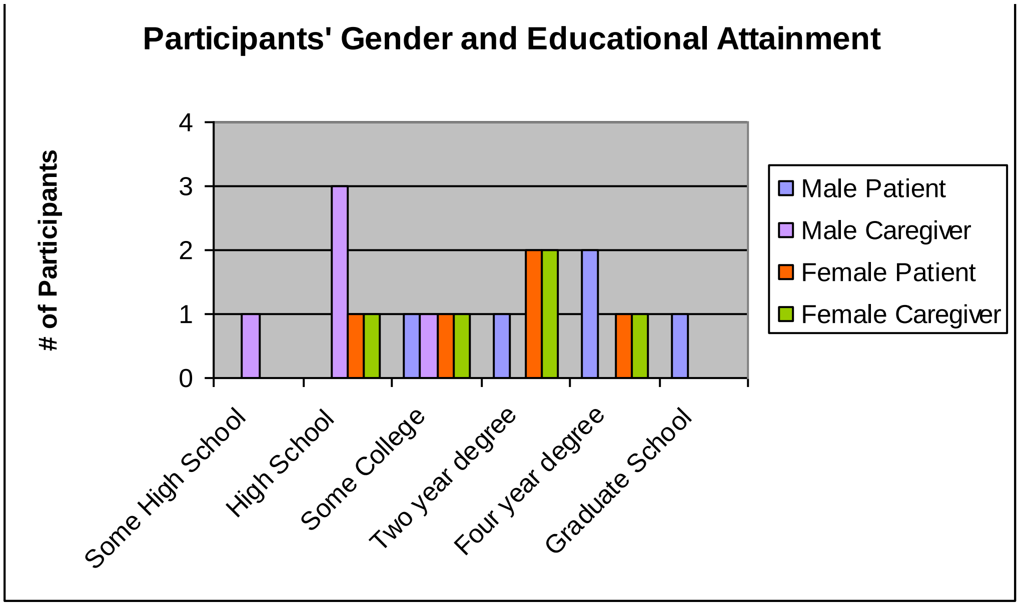

Figure 4: Gender caregiver versus patient education level

Male patients in this study were the highest educated and male caregivers were the least educated. The median education range for male patients was reported as a two or four year college degree and the male caregivers reported their education as a high school education. Female caregivers and female patients reported the same education level, i.e., a 2 year degree,

Household economic status ranged from less than $20,000 to over $100,000 with the median household income range reported as $36,000-$50,000. Two patient participants declined reporting household income. Nine of the 10 couples fell into this income range. Four of the female patients were unemployed, and one worked outside of the home. Three of the male patients were unemployed and two worked outside of the home. All five of the female caregivers worked outside of the home. Two of the male caregivers worked outside of the home and three were unemployed.

Financial concerns and joblessness cause additional distress for families with MS. Lack of financial resources can adversely affect the experience and decrease options for families.

Identified Themes

Permeating and consistent themes emerged in both the reflective journal writing process and during NVivo analysis. These were coded into 25 content areas by the researcher. Eight of those were sub coded into additional specific substance areas. Physical symptoms and care activities were the most frequently discussed content areas during the interviews with 21 sources (actual interviews) identified for each. Physical symptoms were discussed a total of 53 times within those interviews and care activities were discussed 57 times in the 29 interviews. Other topics of frequent discussion include: gender roles (26 times), emotions (24times), life stressors (18 times) and loss (14 times) The following table, Table 1, shows the categories and subcategories, including the number of sources and references that were developed during analysis.

Participant Portraits

I will present 4 couple portraits to give an understanding and feel for the participants in this study.

Table 1: Identified Themes

Category subcategory	Sources/Interviews	Referenced
Care activities	21	57
amount of care	12	15
care needs	17	32
caregiver care for patient	12	24
patient caring for caregiver	9	14
patient self-care	6	6
caregiver self-care	5	5
Physical Symptoms	21	53
Gender roles	14	26
Emotions	12	24
acceptance	5	7
anger	3	3
anxiety	4	5
blame	2	2
depression	3	5
guilt	1	1
hate	1	1
relief	1	1
sadness	1	1
stubbornness	5	8
uncertainty	7	14
Life stressors	13	18
Loss	8	14
Severity 1-10 scale	13	13
Other guy has it worse	9	10
Support systems	2	4
caregiver support	4	4
family support	15	24
friends	6	7
professional assistance	5	5
support groups	11	14

Julie and Mike have four children living in the home. Julie works as an administrative assistant and Mike is a high school teacher. Mike has MS. He has good days and bad days. Mike has the support of his working environment and his Principal makes arrangements so Mike does not have to walk around the building as much as other teachers. Mike loves to attend his children's sporting events, but this is getting increasingly difficult and he is contemplating an electric wheelchair. He fondly remembers playing catch and throwing his kids in the water but he realizes his illness has taken its physical toll. Julie has strong faith and conviction. She believes the husband is the head of the home so she quietly assumes responsibility and gently offers support to Mike without him asking. Julie feels it is important for Mike to be in charge of the family even if he physically cannot manage the home. Both rely on their faith and praise God that his illness is not as bad as others.

Jen has MS. Her husband John attends all medical appointments with Jen because she no longer drives. Jen has an electronic wheelchair and John says she is not good at driving that thing either. Jen requires assistance transferring from chair to toilet. John works at a factory full time and makes sure that Jen has everything she needs before going to work. She has an elderly neighbor to call in an emergency. Jen prefers not to get help from anyone other than John. John reports that others do not know Jen's ways. Jen wonders if John likes her being dependent. John says he does not need another woman in his life because he can do everything now. Jen also talks about her illness and is thankful she does not have MS as bad as others.

Sarah has MS. Sarah and Zack are struggling financially. Zack is looking for work. Sarah talks about the MS "smack down" and wonders if at times she is going crazy. Sarah relies on her parents for help and Zach assists only if Sarah asks. Sarah worries because not only has MS has affected the intimacy in her marriage, but she is also unable to do the tasks she used to do. Sarah is stubborn and one spring she crawled from flower bed to flower bed to get her flowers planted. She says Zack watched but he would not help because she did not want his help. She planted her own flowers that spring.

Not only does Nate have MS, but Nate and Jessica suffer the loss of a teenage son. Nate was active in scouts with his son and his house if filled with scouting memories. Their son never made it to Eagle Scout. Nate is unable to teach anymore. He is on disability and at each and every appointment he asks his doctor if he can return to work. His doctor tells him no. Money is tight for this Nate and Jessica, who are trying to raise teenage daughters. Jessica went to school and now works as a nurse’s aid. She figures she is good at this job because she got used to taking care of Nate. Nate says she might as well get paid for taking care of people because she takes care of Nate for free. Nate has his Bible sitting next to his chair and the baseball game on the television screen. Nate proudly shares his son’s scouting scrapbook. MS is just one of the numerous difficulties he faces.

Care Activities

The most frequently sourced and referenced category in this study was care activities. Participants were able to talk about care in terms of hands on activities completed for the person with MS. Care was discussed either as specific care activities or in broad general terms. Reports of particular care activities varied slightly among participants in the study but had similarity among all participants. Female caregivers reported they provided help with delivering medication, medication management, mobility assistance, activities of daily living (dressing and transferring), cooking, managing finances, memory assistance, financial assistance, attending medical appointments, and providing watchful supervision to the patient. JULIE FC3 stated, “It’s just more of assisting him along and having the watchful eye out a lot.” One male patient, MIKE MP3, described the watchful eye as part of his care receiving experience as well:

> I’ll be a little tired, well; she’ll grab my arm and say she wants me to hold onto her. But really I know what she’s doing, she’s guiding me, making sure that I don’t stagger or fall or anything like that. She’s just more aware of what’s going on around.

Male caregivers similarly report they provide assistance in attending medical appointments, providing household care, house work, assistance with activities of daily living (bathing, laundry, dressing, toileting, and cooking), emotional support, and running errands. Male caregivers also discuss the watchful supervision experience as well. ZACK MC3 reports, “I just can’t get anything done because having to kind of watch her.”

Female caregivers spoke of providing care in broad terms as well. JESSICA FC2 reported, “Well, I know there’s days [sic] he needs more assistance than others. It’s like I have to keep a watch out, making sure he doesn’t fall or something like that.” JULIE FC3 similarly stated, “Doing what I can and just watching out that way…it’s just more of, assisting him along and you know having a watchful eye out a lot…I can tell when he needs a hand out or he needs help getting up” Male caregivers also spoke in broad terms as well. BOB MC1 said, “She’s comfortable with me because I know her ways.” And NATE MC2 said: “I keep an eye on her.” However, male caregivers typically spoke more concretely about care activities such as bringing their wife to doctor’s appointments, helping in and out of the bath tub, cooking, laundry, housework, medication management, warming up the car, vacuuming, and dusting.

Caregivers were also asked about the ways their partners provided care to the caregivers. Participants answered by reporting mostly about physical tasks as opposed to other forms of emotional support. LAURA FC4 acknowledged the difference in the relationship and reported, “I think the thing that I miss somewhat is someone taking care of me once in a while.” She initially described missing the feeling of being cared for; she further explains the activities he is able to complete:

> He’s always there to listen. He does the wash for me. He used to clean the house but he kept running the vacuum cleaner into the baseboards in the walls and I said no more. If I ask him to empty the dishwasher and load it, he’ll do any of that.

A male completing a female task such as doing the wash for her is an example of gender construction. These examples of social construction of gender permeate the caregiver and patient experience. The female has identified wash as her responsibility. Doing laundry is clearly a female task in her experience and her husband completing the laundry is thusly being done to assist her. This is the first of several social constructions of gender statements evident throughout the research.

Male patients discussed providing care to their spouses as well. MIKE MP3 said: “I try to keep an eye on her to not wear herself out. That’s the thing I always worry about, her wearing herself out.” Another, BOB MP1, discussed hands on tasks he completes to provide care for his spouse. He reported:

> I try to help her. She has some stiffness in her back from an auto accident so I might give her massages and so on, things like that. I try to help out around here as much as I can. The house is not immaculate. I can’t get on ladders and get up and get cobwebs and do all that kind of stuff.

A third male patient, KYLE MP5, also reported assisting with household tasks:

> [I] try to let her get rest whenever she has Tylenol. I try to do everything around the house that I can, keep up with everything…I do housework, laundry, dishes, the only thing I don't do is I don't sweep, and that's because sweeping makes me hot and then the hotness makes me have little spells where I have trouble walking so it's not a good thing to do.

Finally, LEN MP4 reported, "This morning I made breakfast because my daughters didn't have school, it got canceled. So I made breakfast for them this morning, pancakes. I do a lot of housework."

Two of the male patients worried about the emotional strain of providing care to a partner with MS. LEN MP4 touched on these worries about his wife in the caregiving role in his comments:

> There's [sic] things you just don't want to tell anybody. You know, I hate to say it, but I mean, I don't want to tell anybody this but every now and then I'll break down and say I've got to tell you something. But if she doesn't need to know it, I try not to tell her.

Len reported it takes an emotional breakdown before he is able to share concerns with his wife/caregiver. In essence, he can only relinquish his role of protector after emotional limitation. This provides an example of society's construction of gender. Culture determines males should protect females and although Len is in the care receiving role, he still maintains his perceived male responsibility of protecting his wife by keeping his problems to himself and only sharing as a last resort.

BOB MP1 also attempts to protect his care provider and reduce the intensity of his physical problems by not sharing the extent of his illness with his wife. He reported, "I don't want to let her really know if I'm having bad days. That's just me, I just don't want to let her know how bad I feel or whatever but I think she sees it."

All participants in the study were asked to quantify the amount of care provided to their partners with MS, but this was difficult for them to do. Responses varied and ranged from SARAH FP3's report of "Oh he does everything. I mean I can't do anything." to MARY FC1's report of "I don't really feel like I do a lot." Several respondents discussed care as part of the overall MS experience. For some, care was established as daily routine and responsibility and therefore not a particular activity to pull out and examine in relationship to the MS experience. MS is one part of life that blends into the whole situation. MARY FC1 reported, "I don't know, some things you just don't even think about, you just do it." Or MIKE MP3 said, "How much she helps me, I couldn't really put a tag on that, because she's thinking about it all the time. Carrying things and she's doing things that I used to do that I never think about doing anymore." Clearly, participants looked at the entire life situation where MS is just one factor and did not pull MS out as a particular condition to understand or respond to.

Particular care activities were similarly discussed by participants with gender differences not seeming to have an effect. Care was discussed as activities or needs for the patient. Male caregivers did speak slightly more concretely about activities and tasks, but this research really shows no difference for a gendered understanding of care activities. This finding supports earlier research that suggests there are no gender differences in the MS care experience (Ybema et al., 2002).

Social Support

Current research indicates that social support is beneficial to the MS patient and the caregiver (Dobrof et al., 2006; Long & Miller, 1991). Specifically, individuals with MS report higher quality of life measurements when they perceive having more social support (Schwartz & Frohner, 2005). Participants described accessing the following types of social support: support groups, professional assistance, friends, family, local MS society chapters, and websites (MS website and Yahoo website). Family support provides the majority of social support, with 12 out of 20 participants receiving assistance from various family members. The 12 participants were equally divided among four groups, 3 participants each in male patient, female caregiver, female patient, and male caregiver groups. Interestingly, family support was the only type of support that male caregivers reported using. Support groups were the next highest utilized method of social support, with a total of 4 participants receiving assistance from support groups: 1 male patient, 1 female caregiver, and 2 female patients were included in this category. Three participants utilized friends as a social support measure: two female patients and one male patient. Two individuals have accessed professional counseling assistance. One female caregiver and one female patient and two male patients reported using local MS society chapters as a means of social support. Table 2 represents the breakdown of identified social support for participants in this study. As reported in the table, all MS patients in the study were receiving some identified form of social support. Two of the female caregivers and two of the male caregivers did not identify any method of social support. Family support, the most frequently identified support measure, was not reported by one male patient dyad and two female patient dyads. The dyad of male patient four did not report family support, as this couple had no family living in the area. (Two adult daughters were married with small children and lived out of state.) The dyads of female patients two and five also had no available family support. Female patient two was childless with aging adult parents, and female patient five had young children and aging parents. Availability of support is also relevant in understanding the use of that support. While the table

Table 2: Identified Social Support

	Male Patients	Female Caregivers	Female Patients	Male Caregivers
Support Groups	MP1	FC4	FP3 FP1	
Professional Assistance			FP5	
Friend Support	MP4		FP1 FP3	
Family Support	MP2 MP3 MP5	FC1 FC3 FC5	FP1 FP3 FP4	MC1 MC3 MC4
MS Society	MP2 MP4			
MS website			FP2	
Yahoo Support Group	MP5			
MS exercise class	MP2			

identifies the types of social support reported by participants, the actual utilization of that support may depend on its availability, i.e., it may not be a matter of choice.

Current research concludes that caregivers are not receiving social support from professionals (Buchanan et al., 2009; O'Hara et al., 2004). In this study, 4 participants or 40% of the caregivers were not receiving any identified form of social support, supporting earlier findings that caregivers are not receiving as much social support as MS patients and could potentially benefit from receiving more support.

Furthermore, caregivers and patients reported trying various support measures but not committing to them long term. BOB MC1 reported, “[S]he went to an MS support group and we did it for a while. But she was bored with it. So if she doesn’t want to do it, I don’t make her.” BOB MP1 stated:

> There was a support group that meets on the last Thursday of every month. I went steady for a while, but I’ve kind of been missing them. Because I forget about them and I don’t have them marked on the little phone calendar.

NATE MP2 identified financial concerns as a barrier to participation in support measures:

> I was a member of what was called the Lunch Bunch. We would go to different restaurants; well, I can’t afford to go out to the different restaurants, you know, once a month and do that. So I haven’t been going. I just can’t afford it.

KATE FP5 sought professional assistance from a psychologist but suspended treatment:

> I don’t talk to Dr. X anymore, and the reason I don’t and I hope she don’t [sic] take it personally, because I really like Dr. X but I quit going to Dr. X because I just have so many doctors that I go to and I have so many prescriptions that I have to pay for… I can’t afford it.

These participants suggest that barriers to consistently accessing some support systems include financial concerns, boredom, and forgetfulness.

Family support, the most identified method of social support by these participants, was experienced by 12 of the 20 participants, patients and caregivers alike. Primarily, family support was discussed in terms of physical support activities. MARY FC1 reported that the sons-in-law help around the house “if we need something and we call…they’ll be here…like…something heavy that he can’t lift, the boys will do it.” CARA FC5 discussed her family helping out “only if we ask them to do something” and said that her aunt is available for assistance on family vacations, which are a challenge for her husband. KYLE MP5 reported:

> They've been on two family vacations without me, one to Disney World and one to Myrtle Beach. There's no reason for me to go and sit in a motel room. That just wouldn't be very fun. The heat's too much for me.

CARA FC5 also reported her own daughters assist. Her elder daughter "brings him things or picks up things for him if he asks and she's in a good mood." Understandably, MS potentially affects the entire family system, not just the patient and caregiver. In the current study, patients and caregivers alike interpreted family as a significant support system that is utilized by both groups, regardless of gender. The noted difference is not between genders, but rather between the reported support systems of caregivers versus patients. Caregivers are receiving notably less social support, which correlates with findings by O'Hara and colleagues (2004) l and Buchanan and colleagues (2009).

Traditional Gender Roles

Unlike the previously discussed care activities and social support, gender in this study impacted the care experience of providing care to MS patients with a connection to traditional gender roles and expectations. Similarly, prior research on gender demonstrated a correlation between gender and differences in providing care and experiencing the care situation (Boeije & Van Doorne-Huiskes, 2003). Social construction of gender defines behaviors and actions as predominantly male or female, and participants in this study placed gender expectations on responsibilities associated with caregiving. Traditional gender roles are altered when either the MS patient or caregiver is unable to fulfill these expectations. For example, women traditionally cook, and if a female with MS is unable to fulfill this expectation, then her husband the caregiver may need to fill that role and cook for the family. This is especially true if no other female is available to cook or conduct other specific gendered tasks. This can be illustrated by how participants in the study discuss this situation and its effects.

LAURA FC4 acknowledged the overall impact that MS has on a male as being more difficult for a male to experience than a female. She states, “Can you imagine how a male feels, having that problem? It’s hard. It’s harder on them than it is on us.” She goes on to say, “He’s always there to listen. He does the wash for me. He used to clean the house.” CARA FC5 said her husband “…helps out around the house a lot, which in my mind is showing he cares…He’s really a big helper, I mean, as much as he can.”

BOB MP1 described the experience of having a disease that is more common among women as, “Why couldn’t I have something that’s a man’s disease? Oh, women have it five times greater than men. I’m in the one percent.” Social construction of the disease tells Bob that MS is a feminine disease. This belief provides a source of discrepancy for this patient. His understanding of the disease is further challenged by the notion that this is a girl’s disease, which for him holds negative connotations.

Other participants recognized a difference in the approaches men and woman take in regard to household responsibilities. DONNA FP4 describes this as:

> Knowing as a woman there’s things that have to be done. Any woman who has any common sense knows that. For some reason some people don’t know that. If I say something to my husband, he’ll do it. But they won’t on their own, just do it.

Social construction of gender is evident for Donna by her understanding that men are unaware of household needs and require prompting. Her husband, caregiver, provides assistance after the female responsibilities have been identified.

BOB MC1 also identified with the impact of gender roles in the care experience. “I think the only thing that’s changed is the responsibilities I have. Because in the early years, all I did was yard work.” His wife in response to this stated, “Okay, so I’ve taught him how to cook and everything, and now he’s so particular, he’s making it even better.” LEN MP4 reported, “Our to-do list has changed, where I was more of the physical, and she was on the phone doing things and now it’s kind of switched around a little bit.” BOB MC1 is responsible for a wide variety of household tasks that fall into the traditional gender role responsibility. He reported:

> I do the laundry, I do the cooking, I do the housecleaning. I do all the running. I do all the finances. Because she can’t, so I just do it all. Now she’ll still go to the grocery with me. Now there’s a good example, when she was healthy, being the American man that we [sic] are, I never went to the grocery with her. She just went and did it. Now, where she’s at the stages in her life now, we do it together.

Caregiver Bob understands and explains his care responsibilities within the context of social construction of gender by acknowledging tasks he believes are primarily feminine. In his role of caregiver he must provide necessary care, which puts him in a position to do what is required, even those jobs he deems intrinsically feminine. Social construction of care tasks becomes the point of conflict for Bob when he must complete tasks that are traditionally a woman’s responsibilities. Bob did not identify mowing the lawn or driving his wife to appointments. Society has defined those as male tasks. Rather, Bob discussed his responsibilities in terms of those unusual to the male experience. Participants were aware of the social construct that divides labor into male and female tasks. When one gender performs a task traditionally attributed to the other gender, this provides a point of awareness and potentially a source of conflict for either caregiver of care receiver.

DAVE MC4 described this as a role reversal:

> It changed; I mean it's almost a role reversal, as far as grocery shopping. She would always do that, take care of that. Well, she can tell you she ain't been to the grocery store in several years now on her own.

BOB MP1 discussed the responsibility of driving: "That's the one job I feel it's my responsibility." And finally, MIKE MP3 explained the gender role impact as follows:

> I've always been the guy that can move things and do things and she could count on me to be that guy that could protect her and stuff like that. Just my feelings, I think it shows her that I'm vulnerable now. And it might be a guy thing where I feel like I've let her down because I'm not able to do the things I could do in the past. She goes, you shouldn't feel that way because you can do this, and you can do that. You can still be the leader of the house and you can still say 'do this and do that.' I said yeah, but there's still a level of respect when you can go and show them how to do it instead of saying go do it. It makes me more dependent on her and it makes her where she's more the leader of the family.

The previous paragraph is rich with gender construction. Mike struggles with his role of husband within the context of having MS. He feels unable to maintain his masculine responsibilities. He reports he is unable to protect his partner or be the leader in his family. He feels vulnerability, which is a trait society attributes to woman.

An expectation of traditional roles and responsibilities associated with gender does affect the care experience with these participants. When either a patient or caregiver was unable to fulfill traditional gender roles, participants reported this as a discrepancy in understanding the MS experience. It seems as if the upheaval of the expected gender roles becomes an abnormality for the participants, both caregivers and patients.

Care Needs

Previous care need researchers suggested conducting in-depth interviews with caregivers while observing daily activities to understand this experience (Sato et al., 1996). While I did conduct in-depth interviews, some in the participants' homes, I did not observe daily activities, although children and grandchildren were present and being cared for by females—both patients and caregivers—in 7 of the 29 interviews. Participants identified several care needs, including increased knowledge of MS, assistance with activities of daily living, assistance with household care, improved medication, financial assistance, durable medical equipment, and patience. Additionally, 2 participants reported that curing the disease would solve the care need problem. Although participants were able to identify various needs, several did not have a plan or solution to meet the need. Several participants engaged with the researcher about knowledge of support groups, medical equipment, and medication questions. It felt as if these participants did not have a venue to discuss their needs and get information about MS that could have provided assistance in their situation. This is another area where gender did not change or affect the MS care experience.

Care and Dependency

Participants discussed the larger concepts of care within the framework of dependency and thus the context of providing care for individuals with MS. We will begin by looking at the comments made by female patients and their male caregiver counterparts. JEN FP1 described an interdependence occurring in her situation: "I know I'm dependent on him a lot and I think he's dependent on me too, emotionally and financially." Another female patient, DONNA FP4, strived for autonomy in the care partnership; maintaining her independence is of great importance to her. She reported:

> I do my very best to do as much as I possibly can on my own. I try to take myself to my appointments for my medication, I drive myself, and I drive myself back. I try as much as I possibly can on my own.

JEN FP1 pondered the issues of dependency and stated, “Sometimes I think he wants me to be dependent on him,” i.e., a need to be needed experience. The social construction of gender evident here refers to the idea that women should be dependent or take the role of dependency in relationships. Jen is somewhat dependent on her caregiver husband, and she understands her husband may find comfort in her dependency, which allows him to be the strong male caregiver.

Jen goes on to say:

> When we had our other house I could take RTA mobility and I had a power chair. But now [in] this house I don’t have a ramp or nothing like that yet. I haven’t been able to do nothing without him. I can’t even get down off the porch without him.

It should be noted, understandably, that this experience varies depending on the severity of the illness. Furthermore, participants did not rate their illness as severe, which at times was contrary to the researcher’s observations.

Two male caregivers were positive when discussing the independence of their partners. NATE MC2 described his partner as “a resourceful girl, you know. I think if something happened she would fall into the support group thing.” FRED MC5 expressed similar thoughts:

> She can do anything she wants to. Just some days she had a little more problem doing it. You know she might be a little slower but she can actually do right now anything she wants to do. She just can’t get up as quick as I would.

BOB MC1 described independence in terms of a loss:

> Seeing her lose her independence. See I know I’ve been pushing it a lot. When I met her she was gung-ho independent. She’s still independent with saying what’s

> on her mind. But I would say that’s the biggest loss, just seeing her lose her independence and going as she pleases.

He went on to say, “She was a very independent person. I think she’s too hard on herself at times, because she…has to fight to put her shoes on. It might take 15-20 minutes to put one shoe on.” Another participant, ZACK MC3, recognized his partner’s inability as well. He reported, “It’s tough because there’s not a whole lot she can do.”

Male patients like MIKE MP3 work to maintain some independence by keeping their physical difficulties to themselves. Mike stated, “I don’t tell her everything that goes on because it’s just going to throw more burden on her, more stress.” However, he did acknowledge the following:

> I am more dependent on her than I used to be, I can say that. I used to be able to say I can go out and do things and not have to have her help. Now I am more dependent on her in that aspect of it. I know its coming. If things keep evolving as they are.

BOB MP1 discussed similar thoughts about dependency with his partner. “You know, I try not to be a burden. You know I sometimes tell her I’m not doing good.” NATE MP2 felt quite dependent on his wife: “If something happened to her, I don’t know what I’d do.” In a similar vein, MIKE MP3 said, “The hardest part is just because I was so active and used to being so physically doing things and I can’t do anything anymore. I mean it’s just hard for me to wash a car.” BOB MP1 described his independence as time spent apart from his wife and acknowledged, “She goes to work, I’m here.” MIKE MP3 also saw time at work as a measure of independence, self-esteem, and identity: “I’m independent because I go to work and I function well. I love my job.”

Female caregivers reported differing responses. LAURA FC4 stated, “He’s dependent on me. I’m not that dependent on him.” The experience for CARA FC5 was quite the opposite: “I’d be very lost without him around. You say they’re your other half, he kind of is just my other half.” Finally, JULIE FC3 described something in between: “Our hearts are dependent on each other, but physically we’re fine without each other.”

Concepts of dependency closely connect with an individual’s ability to receive assistance. Female participants described their ability to accept help as a challenge that encompasses a role reversal. JEN FP1 beautifully illustrated her ability to accept help by stating:

> I guess I didn’t accept help that well at first. I felt like everybody was trying to do everything for me and I don’t think I liked it…sometimes I still don’t, I guess. I’m a little hard on myself sometimes, because I want to try so hard to do things. It’s not that I’m getting mad at them or anything, it’s just I get aggravated with myself.

JEN FP1 went on to report:

> It’s aggravating. I think mostly because I was always so used to taking care of everything. I always took care of everything. I worked a full-time job, I took care of my kids, I cooked, I cleaned the house, I did the laundry, I did everything. My husband just went to work, and that was it and that’s why I can’t believe how well he has just, I mean he can do everything now. He always makes a joke with me, he goes if anything ever happens to you I don’t need another woman because I can do everything now.

For JEN FP1, gender roles and expectations shape her understanding of her care experience. The social construction of gender here again delineates tasks into gendered responsibilities. Jen discusses the traditional life the couple had prior to her inability to complete household tasks and reflects the social construction of gender by reporting her husband has told her he would no longer need a woman because he was able to “do everything now.” Jen internalizes this and may feel unneeded or without value, perhaps further diminishing her self-esteem.

DONNA FP4 described concerns for her husband by saying, “I don’t want him to think he has to stick around and take care of me. I want him to go have a life.”

One male caregiver, DAVE MC4, experienced frustration and wished his wife would accept the available help. “I think what would make it easier if she would use the assistance that she has.”

Male patients expressed difficulty in receiving help as well. For NATE MP2, this was difficult to articulate. He described the situation:

> Sometimes it can be a strain, because it’s hard for me to put in words what help I need. When I need help and when I don’t need help. I’m one of these stubborn A-type personalities that don’t want to admit I need help sometimes. And so some days it’s very obvious and other days it’s not and then I’ll be stubborn.

MIKE MP3’s approach to accepting help was similar to Nate’s: “She helped me with my injections at first, but then I told her I wanted to do it on my own.”

For this study’s participants, gender does have some impact on the issues of care and dependency within the context of gender roles and gender expectations. Again, it appears that the traditional understanding of gendered roles and responsibilities play into the experience of care and dependency, especially if care requires a reversal from the normal expectations. Care and dependency are also impacted by the severity of the individual illness.

Pearlin’s Caregiver Stress Process Model

In addition to the difficulties associated with the diagnosis of MS, patients and caregivers alike experienced a wide range of life situations that contributed to the overall experience with MS. Pearlin’s Stress Process Model offers an explanation of how life

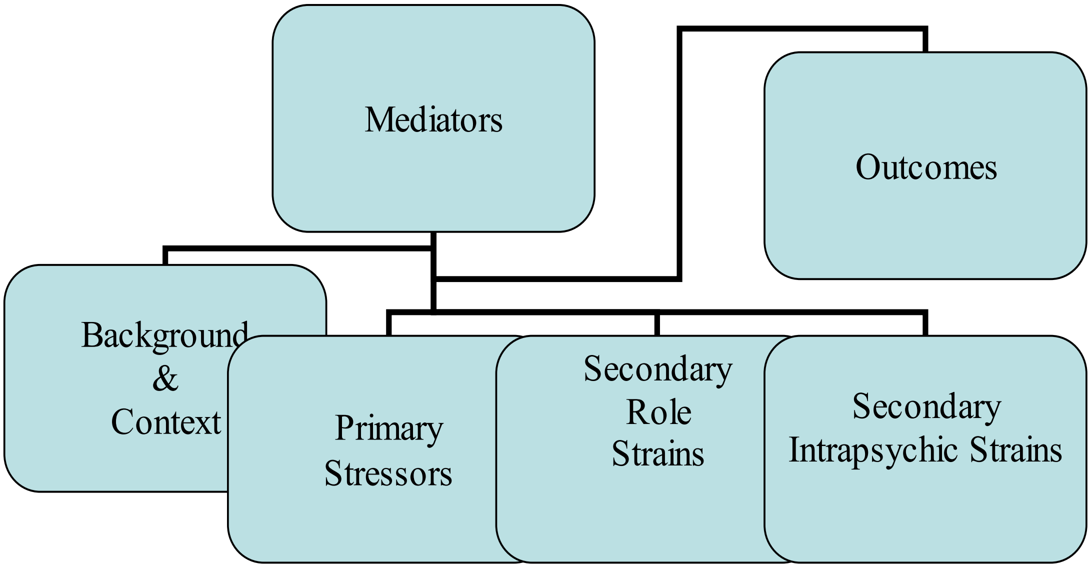

Figure 5: Pearlin’s Caregiver Stress Process Model

Adapted from Pearlin’s Stress Process Model (1990) situations affect the background and context, which ultimately affects the strain experienced by the caregiver. See Figure 5.

We will look at the participants in this research from the perspective of Pearlin's model. Pearlin begins by suggesting the background and context an individual brings to the experience has an impact on his or her overall situation of coping with an illness. Goodman and colleagues (1997) discuss personal orientation as a predictor of caregiver strain, which provides another connection to Pearlin's model in that each individual brings a different standard of coping to the experience. Individual differences in adaptability and coping can be discussed in the background and context of Pearlin's model. Caregivers in the current study discussed a wide range of experiences that shaped the background and context of the MS condition, such as on the job injury, ovarian tumor, loss of a child, diabetes, loss of a job of a caregiver, unemployment of a caregiver, back surgery, insurance company paperwork, financial strain, and problems with employers. MS is not occurring in isolation; rather, it is part of multiple life situations that cause stress and require various coping techniques. All of these situations are outside and in addition to the direct problems associated with MS. The background and context problems contribute to the total experience of coping with MS. For these participants, primary stressors, symptoms directly experienced by the MS patients, were reported as: memory loss, vision problems, weakness in the hands, difficulty walking, pace, numbness, tingling, slurred speech, drop-foot, weakness, difficulty regulating body temperature, falling, loss of stamina, problems with bowls, problems with bladder, stumbling, dizziness, neuropathy, mobility, fatigue, temporary paralyses, and depression.

Participants also experienced secondary role strains as described by Pearlin. Job loss, financial difficulties, and family conflict were part of many caregivers' experience.

To illustrate this BOB MC1 discussed the concept of secondary role strain:

> Only time it becomes a lot [is] if I have a lot of other things to do and I'm trying to get it done and then I have to stop to, you know, meet her needs. But it's not that bad. I guess, it's hard to explain, I guess…if you love your spouse, if love is still there and because something like this happened it shouldn't change your love…you just take on more responsibilities.

He continued:

> I think I push myself too much… she says I push myself too much but like I said it's to the point if I don't do it who is? You know, it's a lot of responsibility. I'm depended on a lot…I just don't think nothing about it it's just something that's got to be done.

The caregivers' secondary intrapsychic strains, e.g., self-esteem, mastery, competence, and improvement, also affected the caregivers' experience. Caregivers in this study did not directly discuss secondary intrapsychic strain but described techniques they used to cope with the illness that correlates specifically with intrapsychic strain. BOB MC1 stated:

> It's been a common question. They'll ask me how you deal with it. Well I have no choice, I have to. If I don't keep going, where will we be then? I might feel sad that this has happened to her, but I block it out. That's the best way I can put it, because like I said…I do it all. So now if I let myself come down, who knows where we'll be. Who knows what chain of reaction that could happen? You know, I love her to death; she's my wife, of course. But I can't let… that pity set in everyday life…emotions plays a big part in MS.

A female caregiver, CARA FC5, said, "I do a lot of praying and I have a lot of family, good friends, if I'm ever having a hard time I can talk to. People at work they're really great." Both of these examples may provide insight into the type of secondary intrapsychic strain the caregivers experienced in their caregiving responsibilities. It appears that caregivers are focused on the patient's illness and less on the strain they themselves may be experiencing as a result of providing care. Throughout the research, caregivers universally focused on the patient's experience and were less concerned with their own situation. Even though participants were told that the research was on the caregiving relationship, participants consistently spoke about and referred to their partner's experience of the illness.

Although, Pearlin's outcomes were not specifically examined in this particular study, correlations can be made in that caregivers experienced a range of emotions associated with the care relationship which can be evaluated under Pearlin's model. Four of the five female caregivers discussed anxiety associated with the caregiving relationship. Anxiety is a clear example of an unfortunate result female caregivers are experiencing. JESSICA FC2 stated, "There's always a worry, you never know what's going to happen." LAURA FC4 described herself: "I'm a great worrier, always have been." MARY FC1 touched on the potential outcome of depression with her comment, "Well, you know, I mean it was sad, I mean you think oh you know life is going to be different and you don't know what to do so you feel a little helpless at first of just not knowing." NATE MC2 had diabetes while caring for his wife with MS and JESSICA FC2 experienced a hysterectomy and lost a son while having care responsibilities for her husband. These physical health problems are discussed as outcomes in Pearlin's model.

Finally, Pearlin's model discusses an individual's ability to cope and notes that access to social support mediates his or her experience and affects the ultimate outcome either positively or negatively. Participants identified the following coping skills: humor, anger, minimization, acceptance, denial, and anxiety. DONNA FP4 summarized her experience with coping with the illness: “Everything I’ve ever done, as far as coping skills, has been bad.”

Using Pearlin’s model, we can see four female caregivers out of five reported anxiety as a result of providing care to a loved one with MS. No male caregivers mentioned or discussed anxiety in these interviews. Gender does seem to play a part in the caregiving experience using Pearlin’s model; female caregivers reported more emotional strain as a result of the care relationship and possibly having more difficulty coping with their caregiving role. Prior research suggests that competing demands and additional responsibilities exist for woman caregivers, which might account for the anxiety experienced by the women caregivers in this study (Stone et al., 1987). Although male caregivers did not specifically speak of feelings of anxiety under the strain of providing care, one male caregiver spoke of “sadness.”

One noted similarity among genders using Pearlin’s model is that caregivers focused on the patient as a primary concern and neglected their own needs in the care relationship. Caregivers communicated the difficulties their partner experience and spoke little of their own hardship. Regardless of gender, caregivers were attentive to their partner’s needs and neglected their own.

Stages of Grief

Several observations I made while writing in my self-reflection journal were centered on identified coping skills that seemed to correlate with seminal writings by Elizabeth Kübler-Ross in her book, *On Death and Dying* (1996), where she identifies stages of grief that individuals experience following a loss. Kübler-Ross discusses denial and isolation, anger, bargaining, depression, and acceptance as the stages one experiences in dealing with grief. Participants in this study also seem to be processing the illness and understanding their experience similarly. Patients and caregivers alike discussed their experience in these familiar grief terms.

Loss

Kübler-Ross's stages of grief allow another unique theoretical perspective to help in understanding the care experience. For patients and caregivers, loss can be experienced in a variety of ways. The loss of physical abilities was expressed by SARAH FP3: "It's so frustrating, I love to work in my flowers and my balance is just gone." She went on to say: "I don't have the ability like to walk through Wal-mart. So I just ride the little scooters." Lastly, she reported she is:

> …mad that I can't just in general do what I want to do, whatever it is. It could be plant flowers, it could be start a business, it could be go to work. You know, whatever it is. It could be going to the bathroom to pee. I had to learn to cath myself.

LEN MP4 described the toughest part for him: "One of the toughest things is not being able to do what I was able to do before. I took so much for granted." Male caregivers discussed loss of physical abilities as well. ZACK MC3 reported, "She gets disoriented because of her balance being off so she just couldn't Jazzercise." BOB MC1 talked about loss:

> Eventually…she was numb in her right fingertips…she starts doing things slower and slower. And then she has trouble driving…then she went from that to started using a cane. Then she went to…grabbing on things …and then she went to the cane. Then she went to the walker, which she still uses a walker in the house but now …a wheelchair. Anything long distance or just when we get out of the house is wheelchair. Because it takes everything she's got, and her coordination's worse. She's weak and she just can't do nothing. You know, the basic abilities.

ZACK MC3 reported:

> We made her quit driving and she's still mad." In terms of gender differences, loss was discussed by three female patients, two male caregivers, one male patient and no female caregivers in this study. In other word, female patients understood their illness as a loss more frequently than male patients, and male caregivers spoke of loss and female caregivers did not. If this is indeed the case, then gender may have a slight connection to understanding of loss with MS.

Denial

A clearer connection to gender can be seen in the use of denial as a coping skill, as denial was discussed by only 4 of the 5 male patients and no female patients. KYLE MP5 stated, "I was in denial for like the first 6 months." MIKE MP 3 said:

> I think part of the reason a lot of people—at least my belief that I don't have it that bad, is almost like a self-defense mechanism. You don't want to believe you've got it that bad because if you think you've got it that bad, then it's that poor me. If you don't think it's that bad then you don't feel like it's oh blah, I'm going to die tomorrow.

He went on to say:

> To be in denial you've got to be early on. You know, not have it for that long; the anger, the denial, the poor me. I don't know how the steps go but you go through those steps, and I think denial is really early.

Kübler-Ross discusses the concept of denial as generally being a temporary defense that will be replaced by some feelings of acceptance (Kübler-Ross, 1969). BOB MP1 reported he and his wife do not really discuss the illness. The conversation between the researcher and BOB MP1 went like this:

> **BOB MP1** "She don't really say too much about the MS"
> **Jennifer** "Do you bring it up?"
> **BOB MP1** "No"
> **Jennifer** "So the two of you don't really talk about it?"
> **BOB MP1** "No, I don't think we really do.
> I mean she knows I'm feeling bad and she knows.
> She saw the changes already.

Using denial as an expression of understanding or as a coping skill seems to have a gender connection in that denial was discussed by four male patients only.

Isolation

Isolation was discussed by 3 female patients, 1 female caregiver, 1 male caregiver, and no male patients. The conversation between the researcher and DONNA FP4 was as follows:

> **DONNA FP4** "I feel like I do it on purpose."
> **Jennifer** "You isolate yourself on purpose?"
> **DONNA FP4**: I do…because I'm a burden. People think I'm drunk. I feel like people look at me like oh my God here she comes oh God. You know, I just feel like nobody wants me. Everybody has someone in their life…where you see somebody and go oh please no or you see the caller ID and go I'm not answering the phone because I don't want to be on the phone for two and a half hours. I feel like that person on the other end. So I don't reach out to anybody because I don't want to be that person. I don't want no one to be afraid of me.

JEN FP1 discussed their change in socialization activities as isolating. She states, "We don't go out and stuff like that like we used to." LAURA FC4 also talked about the illness isolating their participation in social activities. "I know he takes his medicine on Sundays so he doesn't feel good and we don't do as much…But you know, I've slowed way down too. You know we're getting older so it's ok." LAURA FC4 is in her late 40's, which is not generally considered getting old. BOB MC1 discussed isolation of friendships: "Her individual friends…they just stopped coming around…they just don't come around." Isolation appeared to have a more female slant as three female patients and no male patients spoke of feelings of isolation, suggesting some gender connection.

Anger

Anger was experienced by a few participants. BOB MP1 reported, “You know I’m mad about having it. But I’m just like, I just got to go with it.” His care partner also discussed her husband’s anger. “It makes him mad you know.” JULIE FC3 discussed the emotion of anger:

> I would notice he would be short-tempered and he would blow up and say I can’t feel my feet. Can’t feel my right hand. It’s going up my knees, is it ever going to stop? It’s going up to my hips.

DONNA FP4 reported she was angry at:

> Anybody and everybody, myself, God, my aunt who has MS and I don’t know why I’m mad at her but I am. You, know anybody, anybody, everybody, except my kids. It’s not their fault. I’m mad at anybody. There’s a stupid commercial on where this girl, she went to work in New York or something, I guess it was her first job. It was a commercial and she got her debit card and she’s all excited and she’s running around and she’s going to London. Pissed me off! I can’t do that because that’s what I always wanted to do.

MARY FC1 stated, “It makes him mad, you know…Like the weakness in his hands…he’s not good at opening hard stuff anymore or lifting” Anger does not seem to be affected by gender, with one male patient, one female patient and two female caregivers discussing issues of anger.

Bargaining

Bargaining is seen by Kübler-Ross as an attempt to postpone the worsening of the situation by living right (Kübler-Ross, 1969). This feels like a form of magical thinking or a casual reasoning looking for a connection between potentially random events (Zusne & Jones, 1989). No participants specifically discussed bargaining or the use of bargaining techniques; rather, bargaining could be exemplified by a correlation to a faith perspective, which many participants discussed. The belief their relationship with a higher power helps them cope with the illness and possibly lessens the course of the disease was present for several patients and caregivers alike. Specifically, patients and caregivers referred to a faith in God that helps them survive the devastations of this experience. LEN MP4 illustrated this by saying, “God knew before we even knew” and “If you know the Lord’s got a hold of you…I feel comforted knowing he’s there.” LEN MP4 also expressed relief:

> When I first got hit really hard, when I didn’t have any idea what was going on with me. I didn’t know when I had to pee or have bowel movements or anything like that. So you just kind of guess. But praise the Lord it hasn’t happened since.

This could imply that a stronger faith perspective could reduce the severity of the disease or the opposite: Problematic behaviors could in turn cause the disease to worsen. DONNA FP4 discussed a childhood experience:

> I was probably fifteen. My sister was going through some crazy things…so I was getting no attention at all from anybody in my family because they were all worried about her, which I completely understand…I can remember thinking I wish I had something that would make me important. Not anything that would kill me, not any illness that would make me look bad…but just something that would give me attention. And bam, here’s what I got. And it was a onetime weak thought that went away. I always think of that. I don’t think I did anything, but its one of those thoughts that always comes into your mind, well hell you asked for it…I was raised with my mom and dad’s religious background…first of all you don’t go see psychics because you are opening yourself up to evil. And if you say something out loud, you can’t take it back. Nobody can be in the room but that don’t mean that something heard you. Whether it be God, or an angel, or a spirit, or entity or whatever. You’re opening yourself up to whatever and I’m thinking, ‘Somebody heard me say that. It was some evil spirit sitting on the picture frame over there heard me say that or think that and they went oh here you go you can get what you want.

Other concrete examples of magical thinking or a connection between potentially unrelated events are illustrated by both DONNA FP4 and MARY FC1. DONNA FP4 blames a single, selfish childhood thought. MARY FC1 connects an automobile accident with her husband's MS. She reported, "He got hit by another cruiser…which could be one cause. I always think about it …because they don't know." These stories feel like an attempt to show a causal relationship, thoughts to provide understanding or reason, or possibly magical thinking.

Uncertainty and understanding go hand in hand with how caregivers and patients process this disease. Because of the nature of the disease, patients and caregivers really have no way of knowing how their disease will progress. There is no typical course, no typical scenario. This uncertainty accounts for the use of bargaining and magical thinking. Magical thinking goes hand in hand with feelings of uncertainty. Zusne and Jones explain this as:

> Psychologically, the realization that one does not know that one lacks certain information equals the realization that this gap in information must be filled. One experiences a state of cognitive motivation, the motivation to remove the uncertainty. Magical thinking arises in connection with uncertainty concerning cause-effect relationships. A why question requires a because answer. If the information is not available, incorrect information will be used. (Zusne & Jones, 1989)

It is easy to understand how patients and caregivers question their situation and attempt to fill in the blanks with magical thinking.

MARY FC1 wondered, "Is it going to get debilitating? You know, how far is it?" LAURA FC4 discussed uncertainty by saying, "I think it's the unknown. What am I going to do if something happens to him? I just am not in a position where I know what I would do but I will tell you I'll survive!" LEN MP4 tried to explain the uncertainty: "Well, its multiple sclerosis. It attacks people in many ways. We all don't go in and go through the same stage. It can attack you in the eyes, your ears, your legs, your respiratory system, it attacks there…everybody's different."

Gender differences did not account for any discussion of bargaining or magical thinking techniques. One male patient and 1 female patient both used bargaining and magical thinking as a coping technique, and 2 female caregivers similarly discussed these concepts.

Some individuals coped with the illness by increasing their knowledge and thus their understanding of MS. Six participant discussed increasing understanding and knowledge as a way to cope with the illness. Two male patients, 2 female caregivers, and 2 male caregivers discussed acquiring knowledge. The methods used to learn about MS included internet use, library, books, conferences, neurologists, medical facilities, and the MS society.

Another pattern of bargaining or possibly rationalization could be exemplified by the interpretation that other people have the disease worse. Multiple participants coped with the difficulties of their illness by rationalizing that they were more fortunate than others who in their opinion were experiencing worse symptoms. Several patients, who were experiencing severe symptoms themselves, used this form of rationalization or bargaining. Six of the 10 patients interviewed referred to others having the illness worse, as did 2 of the caregivers. In this research, rationalization and a faith perspective both seem to be examples of coping and possibly bargaining. Both themes of faith and the other guy having it worse will be discussed in greater detail later in the chapter.

Depression

Needless to say, individuals coping with MS, both caregivers and patients, experience feelings of depression, Kübler-Ross's fourth stage of grief. Feelings of sadness, hopelessness, or helplessness were experienced by 3 female caregivers, 1 female patient, and 3 male patients. MARY FC1 was asked how she coped with finding out her husband had MS. She reported, "It was sad; I mean you think…life is going to be different. And you don't know what to do, so you feel a little helpless at first of just not knowing." DONNA FP4 illustrated the helplessness by saying, "I just feel like I'm broken and I can't be fixed." LEN MP4 explained in rather direct terms what he experienced:

> I went into depression, clinical depression and still to this day when I think about it, and I try not to, I get, I don't know if it's angry of just you know… I just get really down about it if I think about it. But if I don't think about it and I try not to.

BOB MP1 reported: "I was just devastated. Didn't know what to say or know what to do. LAURA FC4 disclosed, "I'm on depression medicine too, just very mild." One female caregiver expressed concern for her husband's depression. LAURA FC4 acknowledged her spouse's emotional state and said, "He was depressed. He was depressed because of the environment he was in."

JULIE FC3 expressed feelings of helplessness concerning her husband's situation. She explained, "He's been humbled. He's like 'you know, I think I'm humbled enough, but obviously not…another thing happened.' That's where my heart really goes out for him because there's nothing I can do about that." Her partner MIKE MP3 used similar terms:

> It's humbling. It's a humbling experience that you can't do the things you used to be able to do. So you look at it and say, well okay, I don't have that respect level any more. I was really looking forward to that time, to be able to play with them [his children] and work with them and coach them. I was able to coach her and him in basketball but I never got to coach my second son because of it [MS]. So that's where you get to where you kind of get a little depressed.

Three male patients and their corresponding caregivers and no female patients discussed depression; therefore, it seems gender conclusions about depression can be inferred from these results. Male patients are experiencing depression. It is interesting to note the congruency of three male patients *and* their care partners all discussing depression. Couple congruency will be addressed later in the chapter.

Acceptance

Finally, Kübler-Ross's last stage of grief is acceptance. Interestingly, three male patients, one female patient, and one female caregiver discussed a transition from sadness to acceptance or just outright acceptance. MIKE MP3 discussing his use of the coping skill of acceptance:

> But you realize that it just makes you a more better [sic] person because you can't do it that way, but it makes you a better coach, because now you've got to coach it and you can't just show it. You can coach it. So I try to make myself feel a little better that way. But yeah, it's a humbling experience. It makes you modest. It makes you realize that you know things can be taken away from you really quick. And one of the things that it does …it makes you appreciate all the little things. All the little blessings that you just took for granted and you overlooked. You just assumed that was going to happen. You don't do that anymore. At least I don't. I appreciate the little things that happen.

Mike MP3 continues:

> It's workable. My days, I used to have a lot of strong days and a few bad days. Then I'd have two or three good days and a couple bad days. Now there's times when I have good moments and I have bad moments. It just depends. I think it's manageable. I don't think I'm as good as I was five years ago, obviously.

Mike finishes: "You sit there and say Praise the lord, it's still working." SARAH FP3 uses acceptance and said, "Because it's reality. We talk about it and live with it all the time." Her care partner also uses acceptance and said, "It's not always fun, but, you got to do what you got to do." LAURA FC4 stated:

> I'm one of those that will always want to say that the glass is half full. I don't like to be dwelling on the negative, and the energy that you spend on that just doesn't help you. Doesn't get you anywhere, doesn't change the situation. Not to say that I don't have my moments where I'm going to have a down day or something.

LEN MP4 cleverly accepts his situation: "We're going to just keep plugging away. Just keep swimming." This seems to be a reference to the 2003 Disney Pixar film *Finding Nemo*, in which the blue tang fish character Dory sings, "Just keep swimming. Just keep swimming. Just keep swimming, swimming, swimming. What do we do, we swim swim." Dory's pleasant persistence helps her cope with her illness of short term memory loss (Stanton & Unkrich, 2003). Finally, BOB MP1 said:

> I've kind of accepted it already. It's a part of life and I don't want to sit back and moan and groan. You know I tell my wife, I say you know I'm still walking. You know there's more people that are worse off than I am. I've got to be thankful for that.

The 3 male patients' use of acceptance may indicate a slight gendered influence in that only 1 female patient and 1 female caregiver discussed feelings of acceptance. One might infer gender affects the use of acceptance as a coping skill in coping with MS for MS patients, but not caregivers.

Other People Have it Worse

Another theme that emerged in several interviews as a form of coping or rationalization was that others have it worse, i.e., has a more severe form of the disease. Four male patients, 3 female patients, 1 female caregiver, and 1 male caregiver all referenced surviving emotional strains of the illness by attempting to put their illness into the perspective that some other individuals have a worse form of the illness. There appears to be no gender difference in the use of this coping skill, even though the technique is discussed by almost half of the participants, both patients and caregivers. Participants felt they themselves were more fortunate than others with this illness. Even participants who seemed to have rather debilitating forms of MS used this as a coping skill. KIM FP2 reported:

> I think that we live our lives dealing with what's presented to us, like what symptoms or what problem and we kind of cope with that knowing that there are people that are far worse and there are people that are far better.

KATE FP5 rationalized her symptoms as not as severe because she is not having to use personal assistance devices. She said she is "still not what you call severe because I don't need a walker. I need a cane occasionally at times. My symptoms come and go." MIKE MP3 recognized this form of rationalization as a coping skill:

> My belief that I don't have it that bad is almost like a self-defense mechanism. You don't want to believe you've got it that bad because if you think you've got it that bad then it's poor me. If you don't think it's that bad then you don't feel like…I'm going to die tomorrow.

KYLE MP5 said "other people do have the MS worse. We had a little group here in Ohio that we met in Columbus one time…and there was two or three of them that were …in wheel chairs." LEN MP4 spoke of feeling depressed and speaking with others from the MS society:

> There's [sic] a lot of people worse off than me. For a while I was taking water aerobics and there was [sic] some people so bad they had to lower in with a crane. You know, put them in a sling and lower them in. And I quit because of that. I wasn't going to look at that. It just made me even more depressed.

Finally, BOB MP1 stated, "You know, I tell my wife, I say, you know, I'm still walking, you know, there's more people that are worse off than I am. You've got to be thankful for that."

A few caregivers also used a similar line of reasoning as a coping technique.

MARY FC1 told the researcher:

> Well, I always think is it going to get debilitating. When you see different people that have MS, like we go to the seminars and everybody has a cane or a wheelchair or a walker. He goes, 'I'm never going to have any of those'. And I said you might have to.

NATE MC2 said:

> …her symptoms are not that bad. I feel that, you know, we're not as bad off as the other people that you're interviewing maybe. Some of them have more serious issues than what we have. Just from what I've read, from what I've heard and so forth.

ZACK MC3 frankly explained:

> There are people in wheel chairs they make go by blowing into a tube. And all they want is to be as normal as they can be. You know, help me do what I can do for myself. Don't pity me.

Participants thought the use of personal assistance devices was a form of acceptance. It was accepting that MS was winning. Participants did not appear to welcome personal assistance devices; rather, they felt it was a sign of worsening symptoms or weakness. This was experienced twofold—one as a measure of that individual being in a worse situation and the other as accepting their condition as getting more severe. In the joint interview with male patient 5, the couple discussed the following:

> **CARA FC5** "See I think they're thinking once they start, then there's no going back to not using it again.
> **KYLE MP5 "**And that's my idea, I don't want to use the cane because then I'll be stuck with it forever.
> **CARA FC5 "**Yeah, but I think it would help you at times when you are weaker than others.

KATE FP5 framed the severity of her illness by her use of personal assistance devices. She reported:

> It was mild. I would say like a one or a two when I first got it. Now? Still not what you'd call severe because I don't need a walker. I need a cane occasionally at times. My symptoms come and go.

Perception Differences

In looking at the gendered care experience, we examined perception differences between caregiver and care receiver by understanding if the care receiver and care giver rate the illness similarly in terms of severity. Quantifying the severity of the illness was a challenging task for participants. Seven of the 20 participants did not directly respond to the question or rate their or their partner's illness in terms of severity. On a scale of 10, with 10 being the most severe, BOB MP1 rated his illness as a 3 or a 4 and his care partner rated it as a 4. DONNA FP4 felt her illness was a 6 and her care partner rated it as a 5 or 6. KATE FP5 rated her illness as a 4 or 4.5; her care partner felt it was worse and rated it as a 6 or 7. Others reported the severity of illness in words such as "workable", "depends on the day", "not quite severe", or "gotten worse". Three male patients and three female patients answered the question along with four male caregivers and three female care givers. Gender did not seem to affect the perception of severity of the illness.

In the dyad interviews with female patients, four women specifically addressed the concept of perception differences. DONNA FP4 discussed reading both sets of transcripts and noted, "You know…I was tickled at how when I read his [transcript] he saying 'I don't help her do anything' and I'm totally dependent on him in mine [transcript]." This provides one example of a perception difference.

Another isolated example of perception differences is illustrated by BOB MC1's impression of his wife, who feels as if her husband does not understand her MS experience. BOB MC1 shared this impression of his wife:

> Well, you don't know what it's like and you couldn't handle it if you was in this position. And the best answer I give her, I say …no I don't know what it's like but when I met you when you was a healthy normal woman to the present. So I know what you're going through. And too this isn't about me. It's about us, you know, adjusting and doing things to the best way we can to benefit you. And sometimes, then when she's calmed down in a relaxed stage and stuff, she'll say I know. It's just when she gets aggravated.

Perception differences were discussed in 2 of the 10 couples but not significantly enough to report perception differences as affecting the care experience in this research.

Couple Congruence

As noted above, three male patients and their caregivers illustrated couple congruence with their similar description of the male patient's feelings of depression. Another example of couple congruence is shown by couples who report increased marital satisfaction as a result of dealing with the illness. This supports Pakenham's research (2005), which found that multiple caregiver benefits can be experienced despite the chronic sorrow associated with chronic illness. In this research, two male patients and one female patient reported a positive correlation between MS and martial satisfaction. Cara FC5 stated:

> I think he realized that I wasn't going to run away from it. That I was going to stick around and kind of help him through it. So I think it did make our marriage stronger in the beginning, well, I mean, and still. But we depend a lot on each other and [have] pretty open communication about things.

NATE MC2 said his marriage is "maybe a little bit closer, you know, because I'm just keeping a closer eye on her, that's all." ZACK MC3 reported: "For the most part, I think it's made us closer. When I get a little irritated or that she gets irritated back and that creates a problem sometimes." He went on to say: "It seems to me as I remember something about richer or poorer, sickness and health all that. Well she's sick and it ain't her fault. It's not like she wants to be." BOB MP1 also discussed how MS has improved the marriage: "I think it's a good thing. I think we got a little closer, you know, because she's always trying to take care of me." KYLE MP5 said, "I've gotten closer with my wife since I got sick. We do more stuff together, we're together more. So I think it's actually made the marriage work better." DONNA FC4 simply said, "It's [MS] affected it [the marriage], but we still have a good marriage."

On the other hand, 3 additional participants, SARAH FP3, DONNA FP4, and LAURA FC4 expressed uncertainty concerning the affects MS has on the relationship. SARAH FP3 said, "In some ways, you know, it has made us closer. But in other way's it's made it harder." LAURA FC4 said, "Sometimes he doesn't want my help. Sometimes it's hard. It's like finding a balance between being his spouse and being his caregiver. Sometimes you hover too much."

Still other participants reported negative effects on the relationship. DONNA FP4 said, "We don't have a sex life. Well partially because…they've thrown me into menopause. I don't want nothing to do with him…We just don't have the closeness like that. We don't go on dates anymore as much as we used too." DAVE MC4, reflecting on having a wife with MS, said, "I don't want to say disappointing, but it's just, I knew going in when we got married and there's a lot of things we haven't gotten to do things, a family vacation. We've only been on one or two." NATE MP2 reported the following:

> Sometimes it can be a strain, because it's hard for me to put into words what help I need. When I need help and when I don't need help. I'm one of these stubborn

> A-type personalities that don't want to admit I need help sometimes. And so some days it's very obvious and other days it's not and then I'll be stubborn, No I can do it. So sometimes there's a strain, most of the time we're able to--she'll just look at me and say if you need help, I'm not going to do it. I try to stay out of her way. When she's in a mood to do something, I get out of her way. I learned that a long time ago. That's not just MS, that's just marriage.

JEN FP1, KIM FP2, DONNA FP4, BOB MC1, NATE MC2 and BOB MP1all made some reference to problems with sexual intimacy, which was another area of couple congruence. These participants discussed difficulty with movement, lack of desire, and lack of sexual drive. KIM FP2 said, "The only thing is, is that, you know, my sexual drive is just not there." Her partner reported during his individual interview, "Sex isn't the big part of the marriage, you know. And I figure after you're married for a while…it kinda slowed down…the medicine might have an effect on it." JEN FP1 expressed her frustration: "The only thing that has really bugged me, I guess a lot, is I can't move around, get around when it comes to the intimate part. It's kind of like, you know, I'm just laying there." Her partner also reported during his individual interview that "it's not that it doesn't happen, but it has, you know, because for her the desire's just not there." DONNA FP4 stated, "I guess I miss the intimacy of it, just he and I. We just don't have time for that anymore. I just don't have the patience for it anymore." BOB MP1 was concerned about intimacy but only reported that "we just kind of work our way through it."

Four of the 10 couples reported congruence when discussing the affects MS has on their marriage. Two male patients with MS and their caregivers reported the MS situation had a positive effect on the marriage. One male patient/caregiver and one female patient/caregiver reported that MS had a dissatisfying effect on marriage. SARAH FP3 was ambivalent, feeling neither positive nor negative, whereas her care partner reported positive marital effects. Therefore, gender does not appear to have an effect on couple congruence in the current research. Sexual concerns were discussed similarly by two female patient couples, both the patient and the caregiver. One additional female patient and one additional male patient spoke of sexual difficulties, while their care partner did not make reference to any sexual problems in the relationship. As this is a highly private and personal issue which was not specifically addressed in this research, little inference can be made aside from the two female couple dyads that spoke of sexual difficulties along with their care partners during the individual interviews of all 4 participants. This does allow for another example of two couples having a similar experience and understanding of a difficulty in their relationship.

Yet another way couples reported congruence was in their discussions of individual spirituality. Four female caregivers, 3 male patients, and 1 female patient described faith as an important coping mechanism. BOB MP1, MIKE MP3, and LEN MP4, along with their caregivers, all discussed faith as a way to process their experience. MARY FC1 reported, “We have a great faith and I feel that has sustained us a lot…I know a lot of people pray for my husband.” LAURA FC4 said, “I have a strong faith so you just take it and keep on going. Nothing you can do about it.” She questioned: “What would you do without your faith? I can’t imagine people living without one. Mine just keeps on getting deeper and deeper.” CARA FC5 reported, “I do a lot of praying.” Male patients expressed similar spiritual awareness. LEN MP4 reported in the joint interview, “You know the Lord’s got a hold of you and I think that’s the thing that really keeps us laughing with the situation. I’m very comfortable knowing He’s there, that He’s got us in His hands.” MIKE MP3 said, “I’m a very religious guy. So I feel that everything that happens to me is why I feel I know that God's got my path made for me." MIKE MP3 worries about his care partner and talked about how people tell him they are praying for him:

> People don't understand how much pressure it (MS) puts on the caregiver….I just can't tell you how amazed I am at how she handles herself and she deals with it…it makes you know you are loved because she's dealing with things.…I always say people have got to pray for her because there's so much on her.

LEN MP4 also discussed his faith with his wife: "We're pretty strong faith…just put it in God's hands." The couples that experience a similar faith experience are other examples of couple congruence (Pakenham, 2005). The current study found that participants experienced couple congruence in understanding marital satisfaction, sexual experiences, and a faith perspective. Gender differences do not account for couple congruence; rather, that experience varies among topics and couples.

Summary

Gender does play a part in shaping, translating, and understanding the caregiving experience, most notably in regard to traditional gender roles and expectations. When either a care receiver or caregiver is unable to meet these gendered expectations, this results in a change in expectations. Examples of activities that fell outside expected gender roles were a male caregiver having to cook dinner or a female caregiver financially providing for the family.

Concepts of care and dependency were also affected by traditional gender roles and expectations. For some participants, this resulted in feelings of overall gender role reversal. Participants felt "dependent" if they were unable to perform traditional gendered roles such as mowing the lawn, driving, or cooking.

Gender differences were also highlighted using Pearlin's Stress Process Model. Specifically, woman caregivers in this study reported feelings of anxiety as an outcome of providing caregiving, whereas male caregivers did not. This may be connected to the wide range of responsibilities that women experience outside the caregiving situation.

Gender differences were also evident when looking at Kübler-Ross' stages of grief. Specifically, females experienced and discussed more feelings of loss and isolation associated with MS caregiving. Males, on the other hand, displayed feelings of denial, depression, and acceptance. Although mentioned infrequently, gender differences were noted in the discussions and should be further examined in subsequent research.

These gender differences were at times subtle but still remain part of the overall research and the caregiving experience for these 10 couples. Reports of care activities were for the most part quite similar among participants; however, male caregivers did speak in more concrete terms about care activities than their female counterparts. Another area where gender represented a subtle difference was in consideration of areas of social support. Family support was used by all participants; however, it was the only form of support accessed by male caregivers. This also provides for differences that occur between MS patients and caregivers.

In some areas, gender differences were not observed or expressed. It should be mentioned that no outstanding gender differences were noted in two of Kübler-Ross's stages of grief: anger and bargaining. Magical thinking also did not display gender differences among these participants. Another area that resulted in similarities among caregivers regardless of gender was caregivers' focusing on the individual with MS as opposed to their own needs.

Furthermore, no gender differences were evidenced in the discussion of care needs or in the potential of perception differences. Couple congruence similarly did not demonstrate gender differences. Participants reported increased marital satisfaction, decreased marital satisfaction, faith perspective as a coping skill, and concerns about intimacy issues in the marriage. Gender did account for how participants reported their individual situation. The most basic roles and responsibilities associated with caregiving and care receiving are structured by the individual's determination of social construction of gender in the various roles of the task. A socially constructed gendered role affects how the patient and caregiver accept and process responsibility for the task. Gender differences, however, did not account for the rationalization of "the other guy had it worse" or the faith perspective used by several participants as a coping skill.

Clearly, gender is a factor in understanding this experience from both the patient's and the caregiver's lens. Gender is an essential part of this chronic illness and seemingly cannot be factored out of the experience. It is Pearlin's background and context that ultimately factor into the experience, regardless of whether the caregiver is male or female. Their gender ultimately develops the experience.

CHAPTER 5

DISCUSSION

This research begins with an insider's view into being a caregiver for a spouse with MS. This research ends with greater understanding as to how patients and families cope with this life altering illness and how resources are utilized and shifted to maximize advantages.

What became clear while processing my data was my underlying assumption of gender association with particular tasks. These socially constructed beliefs linking gender to particular tasks affect the care experience for caregivers and care receivers alike. Driving the car is a male responsibility and cooking dinner is a female responsibility. Men's work and woman's work concepts are ingrained into society from early experiences, and I thought I would find men caregivers performing typically male related tasks and woman performing typical female tasks. I thought couples would use support systems or other family members to care for patients when assistance was needed, staying mostly within gendered roles. I was looking for reinforcement that individuals remained in a gender role comfort zone and looked for other people to meet gendered care needs. What I found was a relationship of balance among resources and examples of care outside of the gender expectations that left participants with particular consciousness if the task fell outside of the social construct of gender. The most important aspect is meeting the responsibilities of care, and participants use whatever resources are available to do so. Furthermore, participants are aware of responsibilities outside the social construction of gender and completion of those tasks becomes an area of both contention and understanding.

Theoretically I framed this query from a social model of disability perspective using Pearlin's Stress Process Model to unpack the broader care condition in developing an understanding of the entirety of the care experience. I viewed the concepts of care from a feminist care theory lens, or more specifically, the ethics of why individuals provide care in a response to the human condition. These seminal theoretical perspectives set the groundwork for developing an understanding of how the social construction of gendered tasks plays a significant role in the care relationship. From development and linking these theories together, an understanding of the event of providing care can be understood. This roadmap of theoretical integration helps expand an understanding of my research conclusions.

To arrive at my conclusions, the phenomenon of the gender relationship in care for multiple sclerosis patients was explored first by examining how caregivers and those with MS experience the caregiving relationship. Ultimately, the experience of care is affected by the availability and use of resources. In order to understand how someone experiences the care situation, we must first dissect the availability of resources. The care experience varies for people based on the available tools. Caregivers find themselves in the position of making up the difference when resources are unavailable or lacking.

Gender does indeed influence the provision of care and perceptions of care in providing for patients with multiple sclerosis. This begins with the understanding of who should be doing the tasks in the first place. Feelings develop when the responsibility falls outside the parameter of normal for the patient or caregiver. Society plays a significant role in dictating male and female roles. The social construction of gender ultimately influences expectations, roles, and feelings associated with the caregiving experience, both giving and receiving care.

This discussion is further enhanced by the secondary interest in this work: looking at care needs and social support for both care providers and patients. In understanding and developing the care needs and defining the available support, we are able to further the conversation. How participants define care needs and social support helps assess need and develop understanding. The connection of these two research questions allowed the researcher to uncover the importance of the availability of resources and further divide resources into three significant areas: time, people and money. Care needs of both the MS caregiver and care receiver are greatly determined by the availability of resources. Therefore social support in the care relationship becomes a resource that is both available and utilized or a needed resource.

Point of Awareness

Caregivers and patients seemed most conscious of completion of tasks that fell outside the scope of traditional gendered responsibility. For example, a woman patient talks about her male caregiver cooking dinner for her or a male patient speaks about his wife mowing the lawn. Participants seemed most aware of the experiences that fell outside their perception of normal. Participants accepted the tasks typically associated with the gender role and those falling outside that parameter were the point of awareness or a place to discuss in this research. The social construction of gender as behaviors or in the “doing of gender” is formative in understanding this research (West & Zimmerman, 1987). The process of caregiving and care receiving in fact is shaping a new understanding of gender for these participants. A new understanding of completing tasks previously thought to be gendered can be enlightening and developmental for some.

As I thought this through I remembered a personal experience in my role of caregiver. I was pregnant with my fourth child when my husband lost a significant portion of his vision. He was unable to drive. I became fixated with worry about driving myself to the hospital while in labor. As it turned out, I was able to drive myself and my husband to the hospital with no problem. I became really angry about having to drive the family everywhere. I felt embarrassed when others saw me driving all the time. I felt I was being judged by others as being so bossy and controlling that I wouldn’t let my husband drive. I was worried that people would not know he was unable to drive. I’ve gotten over it, but when I reflect on caregiving responsibilities, this is the one that really sticks out as being the most challenging for me to adjust.

Participants

Obtaining participants was more of a challenge than I originally thought. Women patients were more interested in participating and were more readily available. The 5 female patients experienced a more severe form of MS than did male participants, although there is no objective measure of the severity of MS in these participants. Further research could benefit from the use of a functional scale to assess the severity of MS.

I believed I would find female participants with additional support systems outside of their caregiving husbands. I believed these would include other females who assisted with the caregiving relationship. Instead, I found a group of devoted husbands adjusting to their situation. Several of these females did not have an available mother, daughter, or sister. What I learned is that availability of resources is extremely important. Gender differences are a part of the MS caregiving situation, however; families adapt and survive by using available resources. Not all patients have access to a wide range of support systems; therefore, individuals use available assets.

As opposed to the female patient, female caregivers were not especially interested in participation. One male patient and female caregiver declined the joint interview. Actually, they did not respond with a date and a time to meet even after several attempted contacts. Ironically, this particular male patient agreed to participate and reported that his wife was in agreement as well. At the time of the scheduled interview his wife was unable to attend. He gave an understandable excuse and attempts were made to contact her for an individual interview. She did not respond. I ran into the male patient while at the clinic at another time and he apologized and asked me to contact his wife again. I did so and I went to her home for an individual interview. She met with me individually but she did not contact me for the follow-up interview.

Severity of Illness

As I explained, the woman participants were more significantly ill. Their husbands had to transport them to the clinic for appointments and they required assistance driving or ambulating. The caregiver husbands were happy to participate in these interviews because they were sitting around the clinic waiting for their wives. They became a rather captive audience, happy to have someone with whom to share their story.

The male patients did not require driving assistance or help ambulating. Their wives did not come to the clinic appointments. This single difference among the participants does alter research outcomes. I understand it would be difficult to look for research participants and use a certain level of illness as a criteria, especially because people for the most part underrate the severity of their illness and were too busy and uninterested in spending a large amount of time talking about a difficult situation.

Factors to Consider

When I conducted the interviews, I felt as if I had a rather large group of people to speak with, but now I realize that this is a small qualitative study. Individual factors can change the entire situation and story. Dynamics such as employment, available resources, financial concerns, and family composition can change the entire experience for either the caregiver or the participant. One female patient was unemployed as was her husband at the time of the initial interviews. He fortunately got a job shortly after. By the time of the joint interview their particular situation greatly changed, which required the patient to rely on her family for more assistance. When he was not working, he was available to perform care for his wife, and when he returned to work he had less available time to do so. This single factor changed the care dynamics in their family system.

The variety and variation in the participants and severity of illness shed light into the findings of this study, particularly in the understanding of the availability of resources and how that alters the care experience. It also provided insight into how the social construction of gender underlines the care experience in determining a point of awareness for the patients and care providers. If the participants all had access to support and finances, this research might have reinforced the original assumptions made by the researcher—that care providers would provide a level of care consistent with traditional gender roles and responsibilities. If tasks fell outside of the traditional expectations, support people would fill in the gaps. As particular participants did not have access to support people it allowed a deeper exanimation into how these dyads functioned. From there, it became clear that resource availability is a component in processing and understanding the care experience.

Available Resources

In analyzing the use of support systems and further unpacking the use of family support, I became curious about the most frequently utilized support system. Family support was not identified by one male patient and two female patient dyads. I explored the transcripts and indeed these participants did not have access to family support. Crucial in understanding the care experience consequently is acknowledgement of the resources available to patients and caregivers. Individuals utilize resources if and when they are available. Resources in this situation are financial, support measures or available time. Caregivers are left to fill in gaps where available resources are lacking.

The availability of resources can be examined further by looking at the demographic information presented in Chapter Four. All 5 female care givers were employed outside the home, whereas only two of the male caregivers were employed. Furthermore, the male caregivers had the lowest education level of all groups. Lack of financial resources and availability of time for the male caregiver groups contribute to the care experience. If a spouse is not working and lacks money, the couple would utilize available resources and that spouse would find it necessary to provide direct care. With one female patient dyad, the husband was unemployed but the family had a close connection to the female patient's parents who lived down the street and provided much assistance to the family. That particular dyad lacked financial resources but utilized the resource of available family support. Female caregivers all worked outside the home, thus attempting to meet the financial needs of the dyad. Working outside the home decreased the availability of time for these care partners and shifted the caregiving dynamics. A conclusion generated by this research is that the caregiving experience is greatly influenced by availability of three crucial resource elements: time, money, and people. Future research could be conducted with an eye to these three elements: financial resources, support measures or people, and available time. The postulate of the care experience exists:

MONEY (variable) + TIME (variable) + PEOPLE (variable) =

CARE SITUATION (constant)

The caregivers are in a position to make up the difference when resources of money, time, or people are insufficient. A level of basic care is necessary in the care situation and that is a constant.

By formally identifying these elements, practitioners can assist families to maximize their resources in order to optimize their human experience. For example, one family may have ample social support or human capital resources. In this case, the social worker can assist the family in maximally utilizing those resources and at the same time help the families identify ways to improve financial resources by reducing the costs of medication or paid care. The care situation formula is useful in assessing family resources and shifting to provide maximum benefit for families. The amount of required care for one individual is constant at any given time. By reallocating the amount of care among the three elements of care, the social worker can help relieve the burden of care that is imposed by any one of the three elements.

Reallocating can exist between or within the elements. For example, David is stressed in his relationship with Carol because of the amount of care he is providing for Carol. If additional resources can be provided for David through respite care or additional social support, then the relative proportion of care provided by David is decreased slightly and David experiences a reduction in stress.

Continued Research

Continued discussion and research in the area of gender and caregiving can focus on several content areas, including illness severity and access to resources in MS care. An illness severity study could be conducted using a physical ability measure and interviews asking the participants to rate the severity of the illness, as these did not seem to directly correlate in all cases in this study. Participants in this study appeared to underrate the severity of their illness, which poses the question: do MS patients and caregivers provide an accurate understanding of the severity of illness?

Another area for future study is quantitative research focusing on identification of gendered care tasks and use of various support systems by MS caregivers. This research could correlate care responsibilities to support measures and gender. A larger sample could determine if there is statistical significance in the interrelationship of gender, support systems, and care tasks.

Future research could also be conducted with an eye to the three resource elements: financial, support measures or people, and available time. The postulate of the care experience exists:

MONEY (variable) + TIME (variable) + PEOPLE (variable) =
CARE SITUATION (constant)

Future research could attempt to test my postulate and see if it does indeed help to explain MS care situations. This has the greatest potential for transferability to other illness and care situations.

Study Strengths and Limitations

The greatest strength in this study was the researcher’s connection to the participant population. Participants were open and willing to share details of an extremely personal experience with the researcher possibly because of the use of self.

There are limitations to this study. External validity may be a weakness because the extent to which these results can be generalized to other populations may be limited in that MS was the focus of the caregiving population. Transferability is something that could be examined in future research.

Another constraint in this study was securing participants. Attempts were made to have a similar group of research participants; however, getting people to agree to the study was not an easy task. In general, people did not seem interested in participating. I chose a convenience sample but in hindsight a snowball sample may have allowed for a closer selection of participants and would allow for people to talk to people they knew about the study and reassure participants that this would be a safe journey.

I did nothing to account for the severity of the illness and how this could affect the participants. Four of the five woman patients who did participate were significantly ill with MS. The men were higher functioning and had fewer physical symptoms. I attempted to account for the condition of the illness by asking the participants to rate the severity of their illness. This question did not yield the information I had hoped. I knew I was in trouble when the first female patient who was unable to walk without assistance and required her husband to transfer reported that her MS was not that bad. All five of the female patients had some difficulty with movement and mobility. The severity of the illness does play a significant part in understanding caregiving, and self-reports of severity by either the caregivers or the patients are not enough information.

In addition, using patients from the research center may have resulted in the recruitment of individuals who had more frequent appointments and were therefore potentially more ill. Gaining access to individuals with MS and their caregivers is not an easy task. I tried to reduce researcher bias by the conditions of my study, but hand selecting a group of individuals with similarities in condition of illness and resources may have provided richer research information.

Transferability

Information from this study can be utilized in directing future research. This qualitative study provides an in-depth look into the experiences of 10 patients and 10 caregivers and the illness of MS. Understanding gender as a factor also can direct future research focusing on MS patient and caregiver responsibilities prior to their illness and after diagnosis A study could begin by asking participants about gender responsibilities and how MS has changed these responsibilities in their family situation. From a personal perspective, my husband has difficulty seeing and driving is a concern for me. I drive every time we go somewhere together. Reflecting on this, I realize that this one particular gendered task was a source of struggle for me. I was angry at him for making me drive everywhere and I wished he could drive. Was that because driving is a traditional male gendered role? I was completely unaware of this until after I processed the interviews and noticed the gender connection between traditional gender roles. Those traditional gendered roles are so ingrained into our way of thinking that they become a source of struggle for MS patients and caregivers when individuals are expected to perform tasks outside of the normalized expectations.

Implications

This research provides a deeper understanding of the experience of care. This study develops a way to connect with care dyads and help those with illness or those providing care discuss the responsibilities of care in terms of resources: time, financial, and support. Understanding the flexible nature of resources will help social workers assess situations and fill gaps in resources when necessary. Social work educators can focus BSW education on the importance of caregiver relations and resources within the context of care. Social work practice, research, and education can speak of the care situation as a resource assessment focusing on time, finances and people. This becomes a useful tool of assessment and understanding into the window of the MS care experience.

Furthermore, understanding how gender roles color the experience of care can provide insight into the difficulties of this situation. Adaptation to the changes of MS can be evaluated under this deeper understanding. This can also be used in understanding other care situations with a wide variety of illnesses.

Research implications are strong because future research could begin with the postulate of the care experience and have individuals, both caregivers and patients alike describe their situation within the parameters of the formula. From this understanding, the care experience may potentially be quantified into a measurable experience and investigated such that percent of financial resources, social support and time are measures numerically.

Policy implications from this research suggest more assistance needs to be directed to caregivers and the caregiving relationship. Understanding that unpaid care is responsible for a wide range of assistance within caregiving and supporting the caregiving relationship benefits the community and the patient.

Conclusion

Gender shapes the understanding and experience of care. We cannot separate gender from the care experience because we cannot separate gender from our understanding of society. Individuals construct expectations of the role of caregiver by developing understanding into various care responsibilities. The point of awareness for both caregivers and care receivers begins when tasks fall outside their expectation of gender roles. This is the place where adjustment and adaptability occur.

Caregiving dyads use available resources to help develop and support the care needs in the relationship. Understanding resource availability, time, money, and people provides insight into how a particular dyad meets the care needs for both caregiver and care receiver. Resources may change but care is constant and caregivers and care receivers adapt to the situation as resources change.

APPENDIX A

DEMOGRAPHIC QUESTIONNAIRE

Please answer the following questions to provide general information for the study. You may omit any questions you desire.

What is your gender? ____

What is your age? ____

What was the age of onset of multiple sclerosis?

____

Please circle. Are you the care provider or care receiver?

Please circle the letter that best represents your family situation.

What is your economic status?

a. less than $20,000/year
b. $21,00-$35,000/year
c. $36,00-$50,000/year
d. $51,00-$75,00/year
e. $76,00-$99,000/year
f. Over $100,000/year

What is your education level?

a. some high school
b. GED
c. High school
d. Some college
e. 2 year degree
f. 4 year degree
g. Graduate school
h. Professional degree

Who resides in your house? ____

What type of support do you have? (family, outside support, formal support services)____

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Please circle the answer. Are you employed or unemployed?

If you are employed, how many hours do you work each week?

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Please describe your family commitments. (children's activities, care of elderly parent, yard work, church responsibilities)

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APPENDIX B

SEMISTRUCTURED QUESTIONNAIRE

Interview Question Guide:

Research Question: How do caregivers and those diagnosed with MS experience the caregiving relationship?

Interview Guide:

Tell your story of MS.

How would you rate the illness in terms of severity?

How did you deal with the initial diagnosis?

How did your caregiver deal with the initial diagnosis?

How does caregiving/receiving affect your relationship?

Tell me about the care you give/receive.

Research Question: Does gender influence the provision of care and perceptions of care in providing for patients with Multiple Sclerosis?

Interview Guide:

What is it like to be a man/woman with MS?

How do you care for each other?

How do you care for yourself?

How are you dependent on one another?

How are you independent from one another?

Research Question: What are the care needs of both the MS caregiver and care receiver?

Interview Guide:

How many hours of care are given/received during a day/week?

What types of care tasks are being provided by the caregiver?

How is the family unit involved in the care?

How would you rate you or your partner's care needs?

What is needed in terms of your caregiving/receiving?

What would assist you most in your role of caregiver/receiver?

What needs do you have that would assist you in the care relationship?

Research Question: What is the role of social support in the care relationship?

Interview Guide:

What are the other types of care the patient receives aside from the care provided by the primary caregiver?

How is the family unit involved in the care?

Describe any support you receive outside the primary family unit, both professional and nonprofessional.

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